Patients with Heart Failure and their partners

both sides of the picture

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Benefits for patient outcome and impact on the partner's life

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Patients with Heart Failure and their partners:

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General introduction

General introduction

Within our current, western societies several ongoing developments force us to recognize the importance of informal care. One of the most direct consequences of our affluent society is the ageing of the general population. In the Netherlands it has been estimated that in 2020 19% of the total population will be 65 years or older. [1] Furthermore, technological developments in the past decades resulted in far-reaching improvements in medical care. Many new treatment options for patients with several diseases have become available. Especially within the field of cardiology these impressive improvements have resulted in increased survival rates of patients after a myocardial infarction or with congenital heart diseases. [2,3] In combination, these developments have resulted in a growing number of patients with chronic diseases who have to learn to live with increasing, and irreversible limitations and disabilities.

Heart Failure

Among the growing number of chronically ill patients is the population of patients with Heart Failure (HF). The current magnitude of this population has become a significant problem in health care. The prevalence of HF is sometimes described as epidemic. In 2002, the Netherlands counted about 200.000 patients with HF with approximately 50.000 new cases every year. [3] HF is defined as a complex of symptoms and complaints as a result of a failing pump capacity of the heart. [4] Patients develop severe, debilitating symptoms such as oedema, dyspnoea, fatigue and limited vital capacity. Treatment consists of a complex regimen of multiple medications and changes in personal lifestyle. Restricted dietary sodium and fluid intake, maintenance of activity levels and symptom monitoring are important aspects of the management program. [4]

Although options for medical treatment of patients with HF have increased in the past decade with the development of several medications like ACE inhibitors and beta-blockers, and with devices such as the bi-ventricular pacemakers and ICD's, it is becoming clear that future advances will become limited. Despite all efforts, the prognosis of HF patients still remains poor; about 30% of the patients die within one year and 70% will die within five years after diagnosis. [5-7] At the same time the diagnosis of HF is the most frequent reason for hospital admission and for that reason this patient population places a significant economic burden on the health care system and on society. [8] There is a growing conviction that our efforts to improve patient outcome should focus on the quality of life by means of advising and counselling patients in how to adapt to their disease in daily life.

Impact on informal caregivers

Although professional health care is important to HF patients, the largest part of care is provided by informal carers such as partners, or family and neighbours. [9] In the Netherlands, it is estimated that there are millions of people that provide care to another person and this amount will grow with the current trend in health

care of shortening hospitalization and promoting early discharge. [10] The work of informal carers, if it were part of the market economy it would represent an enormous economic value, is more and more recognized as the basis that carries the health care system.

Family caregivers are called upon to provide care to patients at home. Most of this care is provided as it were a natural matter of course and often caregivers derive positive feelings from caring for a beloved one. However, it is also known that many caregivers become burdened at some point. When the need for care increases, the balance between caregiving demands and caregiver capacity may become upset. Caregivers become tired and can feel isolated and overwhelmed. Thus, a chronic illness does not only affect the lives of patients but also the lives of those who care for these patients. The case in box 1 illustrates how support can be provided and how feelings of burden may arise. When acting as an informal caregiver, the partner is stated to provide the most extensive and comprehensive care. [11] Partners display a strong sense of responsibility for co-ordinating care and are less likely to seek and receive assistance. Compared to other caregivers, partners are likely to experience more strain [10,12] and psychiatric morbidity. [13]

Attending to the impact of chronic illness on partners is important because the health and well-being of these caregivers have the potential to influence the health, well-being and rehabilitation of patients with chronic illnesses.

Professional health care

It is clear that when advances in medical treatment for patients with HF become limited, care becomes more and more important. The knowledge that many hospitalizations for HF can be prevented by improving care has resulted in the development of HF management programs and HF clinics. A large amount of studies has indicated that the counselling of HF patients by HF nurses in collaboration with other disciplines, is effective in terms of patient outcome. [14-16]

Within most of the professional heart failure management programs it is recognized that support from spouses or family is important and that a lack of support can render patients vulnerable to repeated hospitalizations. Nonetheless, most HF disease management programs remain focussed on the HF patient and the precise delineation of how to involve partners or family in patient care is never described. In contrast with other illness groups like Alzheimer 's disease or Stroke that have already been studied extensively, there has been surprisingly little interest in the importance of informal care in patients with heart failure. [17]

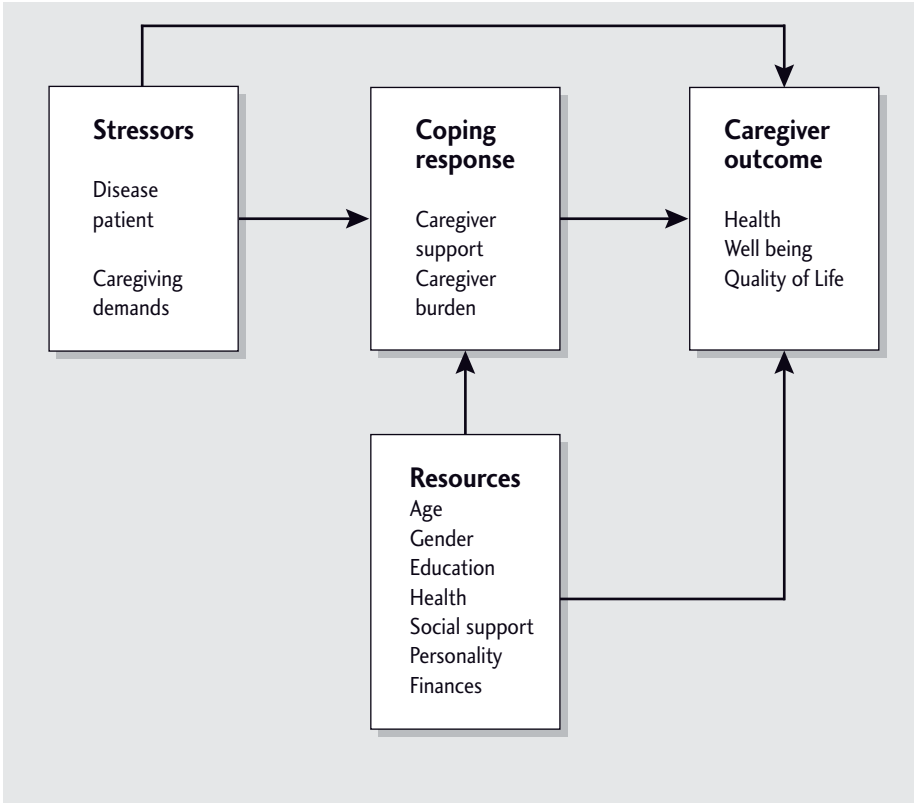
Objective

The objective of this dissertation is twofold, addressing both sides of the caregiving picture. The first part focuses on the impact of having a partner on health outcome in patients with HF. The second part of the dissertation addresses the impact of HF on the lives of partners. Two main questions were formulated;

1. What is the importance of having a partner in terms of health outcome in patients with Heart Failure?
2. In what way does giving care to patients with HF affect the lives of partners?

A theory that is often used to guide research into the concept of caregiving is the cognitive stress theory of Lazarus and Folkman. [18] According to this theory a few key components are to be distinguished in the caregiving process, namely stressors, coping responses and health outcome. In general, the disease or the patient's health is seen as the stressor. The individual coping response depends on a person's resources and appraisal of the situation. Together they will result in caregiver outcome referring to caregiver health and well-being.

Figure 1. Conceptual model for studying the caregiving process



Outline of the thesis

The first part of the thesis comprises two chapters in which the importance of the support of an intimate partner on patient outcome, is described. Chapter 3 provides an overview of the literature regarding existing knowledge in this area. Chapter 4 describes the impact of marital status on quality of life, rehospitalization and mortality in HF patients, using a secondary analysis on data derived from a Dutch intervention study on HF patients. [19]

The second part of the thesis presents studies focussing on the impact of HF on the lives of the caregiving partners. Chapter 5 reports on a qualitative study in which partners of HF patients were interviewed in order to get a first view on their experiences and potential needs. Chapter 6 presents a study on the quality of life of HF partners in comparison to the quality of life in HF patients.

In chapter 7 and 8 results are reported from a sub-study of the Coordinating study on Advising and Counselling in Heart Failure patients (NHF-COACH), of which the design and methodology are described in chapter 2.

While investigating the concept of burden a distinction is made between tangible, objective demands and the appraisal or subjective perception of the situation. Since there were no instruments available to assess the objective caregiving demands on partners of HF patients, a new inventory was developed. In chapter 7 the development and initial evaluation of this new inventory is described. Chapter 8 examines factors that contribute to subjective feelings of caregiver burden. The relative impact of disease severity, objective caregiving demands and partner characteristics on caregiver burden are explored. In chapter 9 the main findings and reflection on these results are being discussed (figure 2).

Box 1 Case study

Mr. B is 67 years old, retired since two years and living with his wife in a single-family home. On their way back from a holiday in France, Mr B increasingly felt sick, tired, short of breath, he had an elevated heartrate but no chest pain. He had never experienced these symptoms before.
Mr B was hospitalized with dyspnoea, fatigue and symptoms of decompensation. Mr B did not have a history of cardiac disease. He smoked about 30 cigarettes and drank about 2-3 alcohol consumptions a day.
During hospitalization Mr B underwent several diagnostic tests with the final conclusion; atrial fibrillation, left ventricle dysfunction with an ejection fraction of 22%. Cardiomyopathy was suggested but no clear evidence was found.
Mr B was discharged after 10 days diagnosed as having HF without a clear underlying cause. HF medication was prescribed; Selokeen Zoc 1x150 mg, Coversyl 1x 4 mg, Furosemide, 2x 20mg, Digoxine 1x ¼ mg, Augmentin 3x 625 mg and Sintromitis based on INR
Furthermore, a sodium-restricted diet and a restricted fluid intake of 1500 ml a day were prescribed.

Part I

Mrs B.

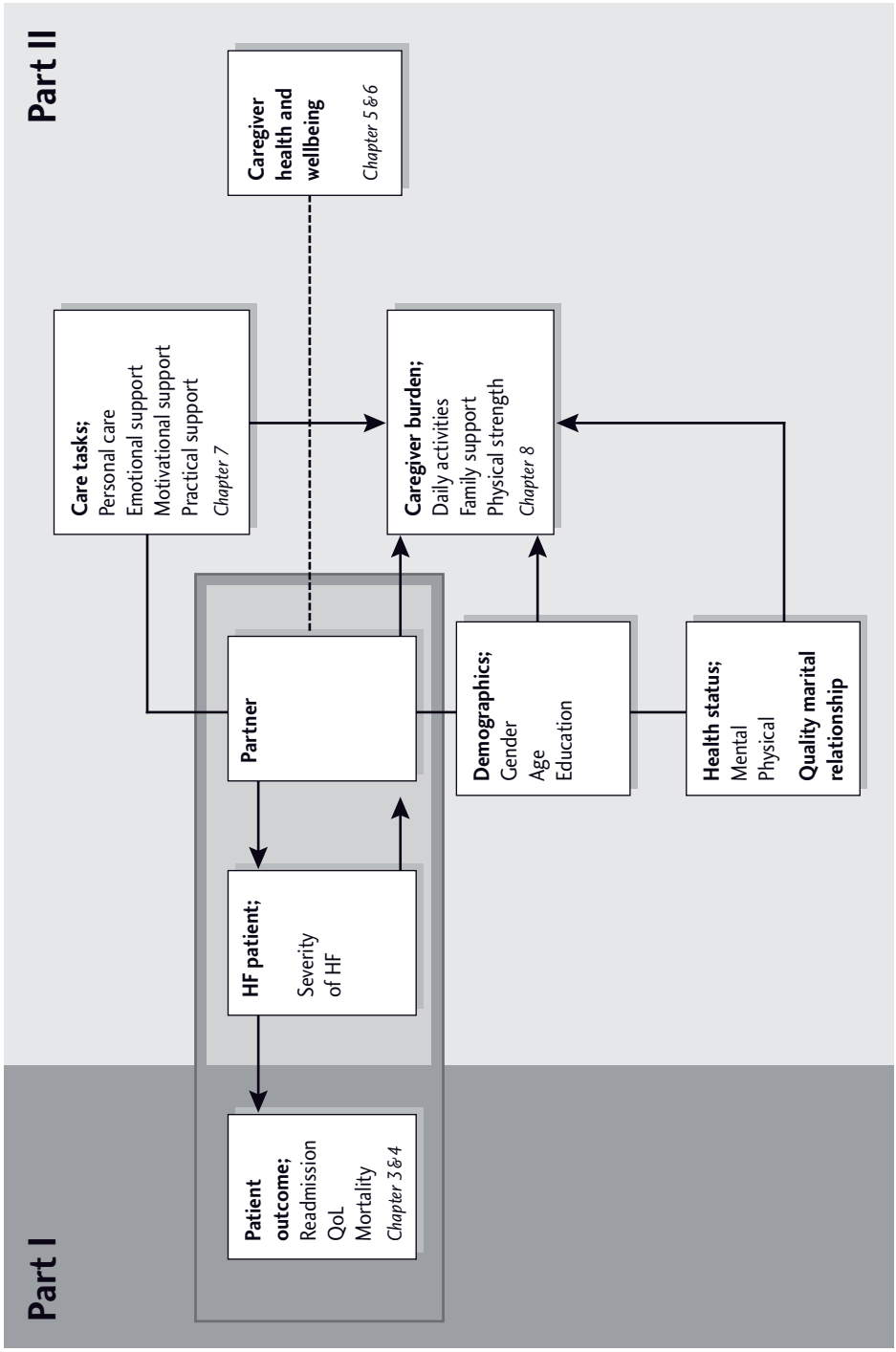
''At first our world was very small. His physical condition was very bad; we lived our life within our home. From the chair to the kitchen, to the toilet and back to the chair and to the bed. Now he has improved and is less dependent on me. But still I have to watch over him. His capacity to concentrate is disturbed. He sometimes forgets his medication or he takes the wrong ones. In stead of his 'evening medication' he takes the dose of the next morning or the other way around. When he does, we fix it by re-scheduling the medication for that day which isn't disastrous but still ……I have to watch…. ……''

Part II

Mrs B

''Life turns out to be not as I expected. I would have liked to continue working, but that was not possible so I made that choice, I quitted working. Then I was a caregiver and in the beginning I was really limited in my daily activities because I did not dare to leave him alone. I was afraid to find him dead after I had been gone.
We used to go out a lot, walking and cycling, but now because of his heart failure, we can't do that anymore. After 10 minutes walking he becomes very tired and short of breath and that's it.
I won't complain, but it is hard for me too. I was used to go out a lot, but now I have to stay at home most of the time. I sometimes go out but not for long, one hour or one-and-a- half at most. I never go out a whole day.
We try to make something of it and we succeed quite well, but there are times when the weather is nice than it hurts to sit inside and watch television……''

Figure 2. Outline of the thesis



References

1 Bakker DH de, Polder JJ, Sluijs EM, Treurniet HF, Hoeymans N, Hingstman L, Poos MJJC, Gijsen R, Griffioen DJ, Velden LFJ van der T. Op één lijn - Toekomstverkenning eerstelijnszorg 2020. RIVM, 2005.

2 Grech V, Savona-Ventura C. Declining mortality from congenital heart disease related to innovations in diagnosis and treatment; a population-based study. *Cardiol Young* 1999; 9:78-80

3 Nederlandse Hartstichting. Hartfalen, cijfers en feiten. Uitgave van de Nederlandse Hartstichting, 2002.

4 Nederlandse Hartstichting & Nederlandse vereniging voor Cardiologie. Multidisciplinaire richtlijn Chronisch Hartfalen. Van Zuiden Communications: Alphen aan den Rijn, 2002.

5 Mosterd A, Cost B, Hoes AW, de Bruijne MC, Deckers JW, Hofman A, Grobbee DE. The prognosis of Heart Failure in the general populations. The Rotterdam Study. *Eur Heart J* 2001; 22:1318-27.

6 Cowie MR, Wood DA, Coats AJS , Thompson SG, Suresh V, Poole-Wilson PA, Sutton GC. Survival of patients with a new diagnosis of heart failure: a population based study. *Heart* 2000; 83:505-10

7 Jaarsveld van CH, Ranchor AV, Kempen GI, Coyne JC, van Veldhuisen DJ, Sanderman R. Epidemiology of heart failure in a community-based study of subjects aged > or = 57 years: incidence and long-term survival. *Eur J Heart Fail* 2006; 8:23-30.

8 McMurray JJV, Stewart S, The burden of heart failure. *Eur Heart J* (suppl D) 2002; D50-D58.

9 O'Connor P. Transitioning Heart Failure Care to the Family. In: Improving outcomes in Heart Failure; an interdisciplinary approach. Aspen Publishers, Inc. 2001, Gaithersburg, Maryland.

10 Boer de AH, Schellingerhout R, Timmermans JM. Mantelzorg in getallen. Sociaal Cultureel Planbureau 2003.

11 Cantor MH. Strain among caregivers: a study of experience in the United States. *Gerontologist* 1983; 23:597-603

12 Nijboer C. Caregiving to patients with colorectal cancer; a longitudinal study on caregiving by partners [Thesis]. Amsterdam: Department of Social Medicine, University Medical Center Amsterdam, University of Amsterdam, 2000.

13 Schulz R, Vistainer P, Williamson GM. Psychiatric and physical morbidity effects of caregiving. *J Gerontol: Psycho Sci* 1990; 181-91.

14 McAlister FA, Fiona ME, Lawson MB, Koon KT, Armstrong PW. A systematic review of randomized trials of disease management programs in Heart Failure. *Am J Med 2001*;110:378-384.

15 Gustafsson F, Arnold JM. Heart Failure clinics and outpatient management: review of the evidence and call for quality assurance. *Eur Heart J* 2004; 25:1596-67.

16 Whellan DJ, Hasselblad V, Peterson E, O'Connor CM, Schulman KA. Metaanalysis and review of heart failure disease management randomized controlled clinical trials. *Am Heart J* 2005; 4:722-29.

17 Molloy GJ, Johnston DW, Witham MD. Family caregiving and congestive heart failure. Review and analysis. *Eur J Heart Fail* 2005; 7:592-603.

18 Lazarus R, Folkman S. *Stress, appraisal and coping*. New York: Springer, 1984.

19 Jaarsma T, Halfens R, Huijer Abu-Saad H, Dracup K, Gorgels T, van Ree J, Stappers J. Effects of education and support on self-care and resource utilization in patients with heart failure. *Eur Heart J* 1999; 20:673-82.

Design and methodology of the COACH study:

a multicenter randomized Coordinating study evaluating Outcomes of Advising and Counselling in Heart Failure

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Adapted from the European Journal of Heart Failure 2004; 6:227-33

Abstract

Background

While there are data to support the use of comprehensive non-pharmacological intervention programs in patients with heart failure (HF), other studies have not confirmed these positive findings. Substantial differences in the type and intensity of disease management programs make it impossible to draw definitive conclusions about the effectiveness, optimal timing and frequency of interventions.

Aims

The aims of the study are:

1 to determine the effectiveness of two interventions (basic support vs intensive support) compared to 'usual care' in HF patients, on time to first major event (HF readmission or death), quality of life and costs.
2 to investigate the role of underlying mechanisms (knowledge, beliefs, self-care behaviour, compliance) on the effectiveness of the two interventions

Methods

This is a randomized controlled trial in which 1050 patients with HF will be randomized into three treatment arms: care as usual, basic education and support or intensive education and support. Outcomes of this study are; time to first major event (HF hospitalization or death), quality of life (Minnesota Living with HF questionnaire, RAND 36 and Ladder of Life) and costs. Data will be collected during initial admission and then 1, 6, 12, and 18 months after discharge. In addition, data on knowledge, beliefs, self-care behaviour and compliance will be collected.

Results

The study started in January 2002 and results are expected at the end of 2005.

Conclusion

This study will help health care providers in future to make rational and informed choices about which components of a HF management program should be expanded and which components can be deleted.

Background

In contrast to favourable trends for most cardiovascular diseases in recent years, the number of patients with chronic heart failure (CHF) is still growing. CHF presents a significant and growing public health problem in industrialized countries and is sometimes referred to as an epidemic.[1] Because the incidence of CHF rises with age, its prevalence will markedly increase as our population ages.[2-4] CHF places a significant economic burden on society, consuming about 1-2% of the health care budget, and a large proportion (approximately 70%) of this is spent on hospitalizations.[3] There is growing evidence that many of these hospitalizations can be prevented by improved patient care.[5,6] Additionally, CHF is a significant burden to patients themselves. CHF has a high mortality rate and patients experience many adverse effects both from the disease and its treatment.[4] Indeed, symptoms such as breathlessness, fatigue and oedema are frequently present, which can substantially affect quality of life.[7]

To improve patient outcomes, a number of HF management programs have been developed and tested over the past twenty years.[8,9] In these programs, several organisational models have been used. Examples of these models are a heart failure clinic, a home based intervention and a hospital outreach program. Key components of all of these models are education and counselling by a heart failure nurse, accessibility of a health care provider in case of problems (mostly a nurse), optimization of medication and increased support after discharge.

To address the effectiveness of HF management programs, a number of randomized controlled studies have been conducted, some of which have reported decreased readmission rates, increased time to first major event, decreased costs and an improvement in quality of life.[10-16] Moreover, a higher survival rate was recently reported in a randomized, controlled trial of a home-based management program in Australia.[17] However, several other studies have failed to support these positive findings, either by reporting negative or inconclusive results.[18-21]

Substantial differences in the type and intensity of disease management programs make it impossible to draw definitive conclusions about the effectiveness, optimal timing and frequency of interventions.

In addition, differences in national health care systems raise questions about the suitability and comparability of HF management programs in different countries. To illustrate this, we have previously reported that an educational intervention with one home visit was not enough to significantly reduce re-hospitalization in a group of Dutch CHF patients.[20] In contrast, Stewart and co-workers have reported a lower readmission rate in a CHF population as a result of a single home visit by a cardiac nurse.[11,17]

It is therefore a major challenge to identify, which program is most effective and the level of intensity required. There are currently no studies that compare the relative effectiveness of different programs.[22]

This background was the rationale for designing the **C**oordinating study evaluating **O**utcomes of **A**dvising and **C**ounselling in **H**eart Failure (**COACH**). In this multicenter randomized study, advising and counselling at two different

intensity levels will be compared to "care as usual" in order to evaluate the level of advising and counselling required. The rationale behind COACH is that if a basic program provides most of the beneficial effect (figure 1), a much more intensive program is unnecessary, and too costly. In contrast, if the effect can *only* be gained by intensive advising and counselling (figure 2) a basic support program may fail to provide that effect. This may indeed explain some of the "negative" studies, which may not have provided *enough* advising and counselling .

In addition to the discussion on **the effectiveness** and **intensity** of interventions, it is vital to identify the mechanisms of action. Some authors state that education; follow-up and availability of a health care provider in case of problems are the most important components of interventions. Others emphasize the importance of compliance to treatment and the early detection and treatment of clinical deterioration, suggesting that these were the key elements in the success of these interventions. Improved knowledge or self-care behaviour of patients are also considered as part of the underlying mechanism for better outcomes. [11,13,14,17]

Finally **a sub-study on partners and partner support** will be conducted. Social support has proven to be of importance in the process of integrating chronic illness into daily life. [23, 24]

Figure 1. Expected event rates if a basic program provides most of the beneficial effect

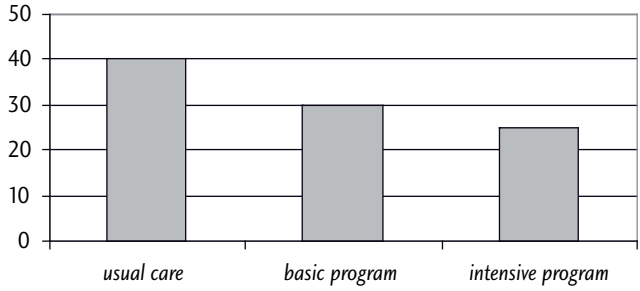
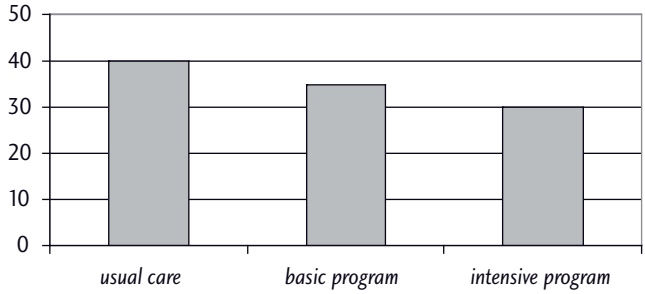


Figure 2. Expected event rates if a significant effect can only be gained by intensive advising and counselling



Methods

Study hypothesis

The hypothesis of the COACH study is that advising and counselling will be beneficial to CHF patients, as compared to "care as usual", in terms of prevention of CHF related mortality and morbidity, as well as quality of life and health care costs.

Primary objective

To determine the effectiveness of two interventions (*basic* support vs. *intensive* support) compared to "care as usual" in CHF patients, on time to first major event (heart failure readmission or death).

Secondary objectives

- To determine the effectiveness of two interventions (*basic* support vs. *intensive* support) compared to "care as usual" in CHF patients, on quality of life and costs.
- To investigate the role of underlying mechanisms (knowledge, beliefs, self-care behaviour, compliance) in the effectiveness of the 2 interventions.

Sub-study

A sub-study will be conducted on partners and partner support. The main objective is to explore the kind and amount of support that partners provide to CHF patients. Furthermore, this sub-study aims to describe the burden of partners who are living with a CHF patient.

Study design

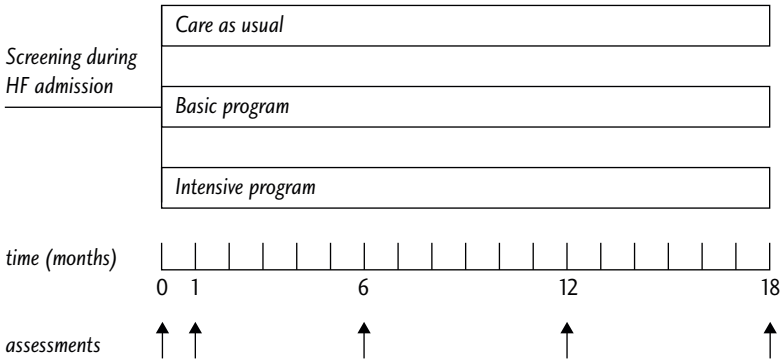
A multicenter, randomized, controlled design will be used. The aim is to recruit 1050 patients with heart failure, randomized into one control group "care as usual" and two experimental groups' basic support or intensive support. The study has been approved by the central Ethics Committee.

For the sub-study on partners a cross-sectional design will be used. Partners will be approached once, at 12 months after randomization of the CHF patient.

Study population

All patients will be required to have a hospital admission for CHF (NYHA II-IV). In addition, patients must be at least 18 years of age, with evidence of structural underlying heart disease. Reasons for exclusion from the study are: concurrent inclusion in a study requiring additional visits to research health care personnel; restrictions that make the patient unable to fill in the data collection forms; invasive intervention within the last 6 months (PTCA, CABG, HTX, valve replacement) or planned during the following 3 months; ongoing evaluation for Heart Transplantation; inability or unwillingness to give informed consent.

Figure 3. Trial design



After confirmation of eligibility according to the above mentioned criteria, patients will be randomized to one of the three intervention strategies, i.e. "care as usual", basic support, or intensive support.

All partners of the participating CHF patients will be approached. The partner was defined as the person the patient indicated to be his/her partner, either married or living together (not married) and residing in the same household. No specific in- or exclusion criteria will be used, except for partners to be able and willing to complete a questionnaire.

Primary endpoint

The primary end point is the time to first event (readmission for CHF or death). A hospitalization for CHF is defined as an unplanned overnight stay in a hospital (different dates for admission and discharge) due to progression of CHF or directly related to CHF.

Secondly, the proportion of 'unfavourable days' during the study will be analyzed. A day is considered as 'unfavourable' if the patient is hospitalized or dead.

In addition, data will be collected on the number of readmission days, number of readmissions per patient and hospitalizations for CHF. Data will be collected by chart reviews, use of databases and interviews.

Secondary endpoints

The secondary endpoints are quality of life, health care costs, compliance, knowledge, beliefs and self-care behaviour.

Assessment, randomization and intervention protocol

Assessment and randomization

Following confirmation of suitability and informed consent, baseline characteristics of the patient will be assessed from the medical chart, patient interview and

patient questionnaires (table 1). After the baseline assessment, patients will be randomized by a central randomization service on a 1:1:1 basis, to either "care-as-usual", basic support or intensive support (figure 3).

Follow-up assessments will take place 1, 6, 12 and 18 months after discharge. Data will be collected at the patient's home by an independent datacollector using a structured interview. Additional data will be collected from the medical chart.

Table 1. Patient questionnaires used in the COACH-study

	Assessment at	Questionnaire
Quality of life	Baseline, 1, 6, 12, 18 months	RAND36
		Ladder of Life
		Minnesota Living with Heart Failure Questionnaire
Knowledge	Baseline, 1, 6, 12, 18 months	Dutch Heart Failure Knowledge Questionnaire
Beliefs	Baseline, 1, 6, 12, 18 months	Beliefs about Compliance Scales
Compliance	Baseline, 1, 6, 12, 18 months	Compliance questionnaire
		Medication Monitoring System, (MEMS®).
		Food diary
Self-care behaviour	Baseline, 1, 6, 12, 18 months	European Heart Failure self-care behaviour scale
Depression	Baseline	CES-D
Type-D	Baseline	Type-D
Reason for readmission	During the study	Reasons for readmission interview

Partners of HF patients will be approached at 12 months after the patient's discharge. Partners will receive a self-report questionnaire at home which will be collected by the independent data-collector. The questionnaire includes several standardized questionnaires and reflects on the status at the time of interview or the time just before the interview (table 2). Partners will be asked to complete the questionnaire independently from the patient.

Table 2. Partner questionnaires used in the COACH-study at 12 months

	Questionnaire
Performed caregiving tasks	Dutch Objective Burden Inventory (DOBI)
Caregiver Burden	Caregiver Reaction Assessment Scale (CRA)
Quality of the marital relationship	Based on Cantril Ladder of life
Quality of life	RAND36
	Cantril Ladder of Life
Knowledge	Dutch Heart Failure Knowledge Questionnaire
Depression	CES-D

Table 3. Treatment and care for patients in the "care as usual" group (control), and intervention groups

	Care as usual	Basic program	Intensive program*
Hospital		Visits by HF Nurse	Visits by HF Nurse Multidisciplinary Advice
1 week			Advising ☎
			Home visit by HF nurse
2 week		Advising ☎	Advising ☎
3 week			Advising ☎
4 week		Visit to HF nurse	Visit to HF nurse
8 week	Visit to cardiologist	Visit to cardiologist	Visit to cardiologist
		Visit to HF nurse	Visit to HF nurse
3 months		Visit to HF nurse	Visit to HF nurse
4 months			☎ Multidisciplinary Advice
5 months			Visit to HF nurse
6 months	Visit to cardiologist	Visit to cardiologist	Visit to cardiologist
		Visit to HF nurse	Visit to HF nurse
7 months			☎
8 months			Visit to HF nurse
9 months		Visit to HF nurse	Visit to HF nurse
10 months			☎
11 months			Home visit by HF nurse
12 months	Visit to cardiologist	Visit to cardiologist	Visit to cardiologist
		Visit to HF nurse	Visit to HF nurse
			Multidisciplinary Advice
13 months			☎
14 months			Visit to HF nurse
15 months		Visit to HF nurse	Visit to HF nurse
16 months			☎
17 months			Visit to HF nurse
18 months	Visit to cardiologist	Visit to cardiologist	Visit to cardiologist
		Visit to HF nurse	Visit to HF nurse

** if needed additional visits or phone calls will be made.*

Treatment and care

Two different types of interventions will be tested and compared to a control group as described below (table 3). The content of the interventions is derived from interventions used in other countries, from interventions that are relevant and realistic in the Netherlands and according to the Dutch Heart Failure Guidelines.

Care-as-usual
Patients in the control group will receive usual treatment and care. After hospital discharge patients assigned to the control group will continue to receive routine management by the cardiologist and, subsequently, by their general practitioner. No extra follow-up by a HF nurse or a multidisciplinary team will be provided. Since counselling and advising by a HF nurse is not the usual care in the Netherlands, this control situation is (still) ethically feasible. Patients will visit the cardiologist at the outpatient clinic according to a defined schedule. This schedule consists of visits to the outpatient clinic 8 weeks after discharge, 6 months, 12 months, and every 6 months thereafter. Patients will be treated using current guidelines, receiving optimal doses of standard medication.

Intervention group 1: Basic support
These patients will receive care from the cardiologist as described above. In addition, the following support will be provided:

- Patient (and family) education according to guidelines and protocol in hospital and during visits to the outpatient clinic. Behavioural strategies will be used to improve compliance.
- A telephone contact will be made within 2 weeks of discharge.
- During their regular visits to the cardiologist at the outpatient clinic patients will also visit the HF nurse. In addition, there will be visits to the heart failure nurse after 4 weeks and then 3, 9 and 15 months after discharge.
- Telephone access to a HF nurse. Patients and their family/carers will be encouraged to contact the nurse if there is a change in the patient's condition or if there are any problems or questions. The nurse can be contacted Monday to Friday 09.00-17.00h.

Intervention group 2: Intensive support
In this group, the most intensive level of advising and counselling will be provided. This means that patients in this group will receive education and counselling similar to that in intervention group 1. The following extra support is provided:

- A home visit will be made within 10 days after discharge from the hospital. The home visit will allow the nurse to assess how the patient is coping in the home environment, the patient's CHF status, the patient's general health status, available medical support, health care and social support and future health care needs based upon this. An additional home visit will be made 11 months after discharge.
- Patients in this group will be contacted each month during the course of the study by the HF nurse (and by their cardiologist during usual visits) If needed, additional visits or telephone calls will be made.
- In the first month telephone calls will be made weekly.
- Telephone availability of a HF nurse during office hours and 24-hour coverage by a back-up system.

- The nurse will consult a multidisciplinary team at least once during hospital admission and once at follow-up to optimize her advice for each patient. This multidisciplinary team will consist of a physiotherapist, dietician and social worker. Other health care professionals will be consulted, as required.

In both intervention groups the HF nurses will use a computer program to guide patient education and counselling. This program consists of an assessment form and patient education topics, which are specified for each patient visit (incl. home visit). Additionally patient progress is reported and the number of patient contacts that are initiated either by the health care provider or by the patients, are registered.

In the training of the HF nurses, the importance of counselling strategies is stressed and explained. In addition to providing information to patients, HF nurses are trained to increase self-efficacy of patients. Material used in the intervention include a patient diary, brochures and samples of sodium restricted seasoning/ spices

Statistical issues

Analysis

All analyses will be conducted according to the intention-to-treat principle. To meet the primary objective in the study, the primary variable 'time to the first hospitalization for heart failure or death will be evaluated using Kaplan-Meier survival analysis. Log-rank testing will be done to compare the different treatment strategies. In addition, a Cox proportional hazard model will be fitted for a multivariate analysis. A p-value below 0.05 will be considered as statistically significant and the incidence curves will be considered to be confirmed different.

Secondly, the proportion of 'unfavourable days' during the study will be analysed. A day is considered as 'unfavourable' if the patient was hospitalized or dead.

Power calculation

The number of 1050 patients in the COACH study is based on the primary endpoint of time to major event. In previous international studies, event rates (hospital admission and/or death) ranging from 30-54% are reported. It should be noted that several studies only include patients with a low ejection fraction and patients in NYHA III-IV. In patients with NYHA II, a lower event rate can be expected. In a Dutch intervention study, a readmission rate of 50% (control) versus 37% (experimental) within 9 months has been reported.[21] The effect-size of nursing interventions vary from a reduction in readmission rates of 27%, 42% or 44%.[11-13] In the current study with an 18 months follow-up period, the event

rate (readmission or mortality) of control patients is estimated at 40% within 1 year. A 25% reduction of the major events in the basic follow up intervention group is considered both realistic and clinically relevant.

It was calculated that 698 subjects (349 in each group) will be needed to detect a 25% reduction in events (power of 90%, alpha of 0.05) in the basic intervention group. For the additional intervention group, another 349 patients will be included.

Moreover, with 349 patients per group, the study has a 90% power to show that the number of 'unfavourable days' reduces by 50% by the intervention - from 60 days to 30 days (sd. 120) during the study period of 18 months.

Study organisation

Study centres

In order to include the 1050 patients in 18 months, 17 hospitals in the Netherlands are participating in this study.

Steering Committee

Prof. Dr. DJ van Veldhuisen, Chairman and Principal Investigator, dr. T. Jaarsma, Principal Investigator, DJA Lok (on behalf of Working Group on Heart Failure of the NVVC), Prof. Dr. KI Lie, Prof. Dr. R Sanderman, Prof. Dr. JGP Tijssen, dr. PHJM Dunselman, Prof. Dr. WH van Gilst, dr. HJ Hillege, Prof. Dr. AW Hoes, Dr. JE Speksnijder and Dr. MCM. Senten (both on behalf of the NHF).

Endpoint Committee

A panel of 2 cardiologists and an internist/geriatrician will judge whether a reported hospitalization of a study participant is related to heart failure (primary endpoint) cardiovascular death or cardiovascular events. The panel will be blind as to whether the patient was in the control group or one of the intervention groups.

Support and monitoring

The study will be supported and monitored by the Trial Coordination Centre (Dr HJ Hillege MD PhD, N Veeger MSc) a contract research organization for clinical trials. Both the quality of the research data and of the intervention will be structurally monitored. To address the quality of the intervention the data from the computer program -which is used for the education and counselling- is monitored and discussed monthly with the HF nurses by an on site visit of a research fellow.

Financial support

The Netherlands Heart Foundation (NHF) financially supports the study as one of their top down research programs (2000Z003).

Conclusion

To obtain an insight into the optimization of education and counselling of HF patients, this multi-centre randomized trial, aims to include 1050 HF patients. Results from this trial, which recently started recruitment, will help health care providers in future to make rational and informed choices about which components of a HF management program should be expanded and which components can possibly be deleted.

References

1 Cowie MR, Mosterd A, Wood DA, Deckers JW, Poole-Wilson PA, Sutton GC, Grobbee DE. The epidemiology of heart failure. *Eur Heart J* 1997; 18:209-25.

2 Bonneux L, Barendregt JJ, Meeter K, Bonsel GJ, van der Maas PJ. Estimating clinical morbidity due to ischemic heart disease and congestive heart failure: the future rise of heart failure. *Am J Public Health* 1994; 84:20-8.

3 Berry C, Murdoch DR, McMurray JJ. Economics of chronic heart failure. *Eur J Heart Fail* 2001; 3:283-91.

4 Stewart S, MacIntyre K, Hole DJ, Capewell S, McMurray JJ. More 'malignant' than cancer? Five-year survival following a first admission for heart failure. *Eur J Heart Fail* 2001; 3:315-22.

5 Vinson JM, Rich MW, Sperry JC. Early readmission of elderly patients with congestive heart failure. *J Am Geriatr Soc* 1990; 38:1290-95.

6 Michalsen A, Konig G, Thimme W. Preventable causative factors leading to hospital admission with decompensated heart failure. *Heart* 1998; 80:437-41.

7 Jaarsma T, Halfens R, Huijer Abu-Saad H, Dracup K, Stappers J, van Ree J. Quality of life in older patients with systolic and diastolic heart failure. *Eur J Heart Fail* 1999; 1:151-60.

8 Rich MW. Heart failure disease management: a critical review. *J Card Fail* 1999; 5:64-75.

9 McAlister FA, Lawson FM, Teo KK, Armstrong PW. A systematic review of randomized trials of disease management programs in heart failure. *Am J Med* 2001; 110:378-84.

10 Rich MW, Beckham V, Wittenberg C, Leven CL, Freedland KE, Carney RM. A multidisciplinary intervention to prevent the readmission of elderly patients with congestive heart failure. *N Engl J Med* 1995; 333:1190-5.

11 Stewart S, Marley JE, Horowitz JD. Effects of a multidisciplinary, home-based intervention on unplanned readmissions and survival among patients with chronic congestive heart failure: a randomised controlled study. *Lancet* 1999; 354:1077-83.

12 Cline CMJ, Israelsson BYA, Willenheimer RB, Broms K, Erhardt LR. Cost effective management program for heart failure reduces hospitalization. *Heart* 1998; 80:442-6.

13 Naylor MD, Brooten D, Cambell R, et al. Comprehensive discharge planning and home follow-up of hospitalized elders: a randomized clinical trial. *JAMA* 1999; 281:613-20.

14 Krumholz HM, Amatruda J, Smith GL, et al. Randomized trial of an education and support intervention to prevent readmission of patients with heart failure. *J Am Coll Cardiol* 2002; 39:83-9.

15 McDonald K, Ledwidge M, Cahill J, Quigley P, Maurer B, Travers B, Ryder M, Kieran E, Timmons L, Ryan E. Heart failure management: Multidisciplinary care has intrinsic benefit above the optimization of medical care. *J Card Fail* 2002; 8:142-8.

16 Kasper EK, Gerstenblith G, Hefter G, Van Anden E, Brinker JA, Thiemann DR, Terrin M, Forman S, Gottlieb SH. A randomized trial of the efficacy of multidisciplinary care in heart failure outpatients at high risk of hospital readmission. *J Am Coll Cardiol* 2002; 39:0471-80.

17 Stewart S, Horowitz JD. Home-based intervention in congestive heart failure: long-term implications on readmission and survival. *Circulation* 2002; 105:2861-6.

18 Weinberger M, Oddone EZ, Henderson WG. Does increased access to primary care reduce hospital readmissions? *N Engl J Med* 1996; 334:1441-7.

19 Ekman I, Andersson B, Ehnfors M, Matejka G, Persson B, Fagerberg B. Feasibility of a nurse-monitored, outpatient-care program for elderly patients with moderate-to-severe, chronic heart failure. *Eur Heart J* 1998; 19:1254-60.
20 Jaarsma T, Halfens R, Huijer Abu-Saad H, Dracup K, Gorgels A, van Ree J, Stappers J. Effects of education and support on self-care and resource utilization in patients with heart failure. *Eur Heart J* 1999; 20:673-82
21 Doughty RN, Wright SP, Pearl A, Walsh HJ, Muncaster S, Whalley GA, Gamble G, Sharpe N. Randomized controlled trial of integrated heart failure management. *Eur Heart J* 2002; 23:139-46.
22 Moser DK, Mann D. Improving outcomes in heart failure: it;'s not unusual beyond usual care. (editorial). *Circulation* 2002; 105:2810-12.
23 Berkman LF. The role of social relations in health promotion. *Psychosom Med* 1995; 57:245-54
24 Reifman A. Social relationships, recovery from illness, and survival: A literature review. *Ann Behav Med* 1995; 17:124-31

Partners:
the importance for patient outcome

Impact and Importance of social support on outcomes in patients with Heart Failure:
an overview of the literature

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Abstract

Background

As advances in medical treatment of Heart Failure (HF) become limited, other factors are being studied to improve outcomes. There is much evidence that supportive social relations have a major impact on health outcomes and that social support is essential for adjustment to illness. This article describes current research on the influence of social support on outcomes in patients with HF.

Methods

A computerized literature search in Medline, CINAHL and PsychLit was performed on each of the different outcomes in relation to social support, covering the period 1993 to 2003.

Results

Seventeen studies were found that investigated the relationship between social support and different outcome measures in HF. Four studies found clear relationships between social support and rehospitalizations and mortality; the relationship between Quality of Life (QoL) and depression was less clear.

Conclusion

Up to now, limited research has been done on the impact of social support on outcomes in patients with HF. The available studies suggest that social support has an impact on outcomes in patients with HF but further research is necessary before firm conclusions about the nature of these relationships can be reached.

Introduction

Heart failure (HF) is often defined as 'a patho-physiologic state in which an abnormality of cardiac function is responsible for the failure of the heart to pump blood at a rate commensurate with the requirements of the metabolizing tissues'. [1] HF is a serious, chronic and incurable illness which has a major impact on the lives of patients. Severe symptoms such as dyspnoea and fatigue, limited vital capacity, and the consequences of treatment affect not only physical but also mental and social aspects of life.

Despite important advances in medical management of HF, the prognosis of patients with HF remains poor. Mortality and hospital admission rates are high. [2,3]

The treatment of HF is complex and often primarily aimed not at recovery but on outcomes such as survival, reduction in readmission rates and improvement in quality of life. These aims are met by promoting self-care [4] so that patients can successfully follow a complex regimen of multiple medications, dietary sodium restriction, increase or maintenance of activity levels, symptom monitoring and, for some patients, fluid restriction. Because of the complexity of the regimen, and problems with patient adherence to recommendations, substantial effort has been undertaken to improve care by using multidisciplinary HF disease management programs. These programs are often nurse-directed and aimed at advising and counselling the patients on how to deal with the prescribed regimen in the hospital as well as after discharge. [5] A major component of these programs is the support of health care professionals as patients cope with and adjust to necessary lifestyle changes. Equally important to helping patients to achieve optimal self-care is promoting and enhancing the support patients receive from partners and relatives.

There is much evidence that supportive social relations have a major impact on health outcomes [6] and that social support is essential for adjustment to illness. [7] The processes and mechanisms linking social relationships to health may be physiological or behavioural. [8]

In most HF disease management programs, it is recognized that the support resources of the patient are important and lack of resources can render patients vulnerable to repeated rehospitalizations. Nonetheless, in most HF disease management programs the intervention remains focused on the patient, without explicit delineation of how the partner or family should be involved. As a result, inclusion of partners or other family members is haphazard at best.

Although research has demonstrated that social support is a major determinant of adjustment to coronary artery disease (CAD), [9-11] up to now, little research has been done on this issue in patients with HF.

Therefore, the purpose of this article is to review the literature on what is scientifically known about the impact of social support on outcomes in HF patients.

Definitions and concepts

Although the concept social support is already broadly used, different definitions exist. There are various theoretical views on social support, and as a result many different approaches are used to examine this concept. A commonly used framework is that developed by House et al, [12] in which social support is divided into three broad categories: social integration, social networks and relational content, including positive and negative aspects of social interaction.

Social integration refers to social ties such as marital status, having close family and friends and the degree of participation in groups and religious affiliations.

Social networks are structural properties of social relationships, are typically measured by characteristics such as size (number of people), reciprocity (equal exchange between people), and density (degree to which members of the person's network interact with each other).

Relational content refers to the functional aspects or quality of social relationships. In this category the term social support refers to the 'positive, potentially health promoting or stress-buffering aspects of relationships'. Relational content includes three types of support: emotional (caring, physical affection), instrumental (tangible assistance or material goods) and informational (provision of information and advice).

According to Cantor's model of hierarchical compensation, [13] older adults select their support from a hierarchy of supportive relationships. Family members are always selected first and within the family, the spouse and the children are chosen more often than distant relatives. Within non-family, friends and neighbours are chosen before individuals from formal organizations. In practice, social support is provided by partners or spouses most of the time.

To review the literature on the impact of social support on outcomes in HF patients, the broad meaning of the concept of social support is considered.

Mechanisms

There are several models to explain how social support influences physical health outcomes. According to Cohen [8] there are 2 general mechanisms that link social support to disease; physiologic and behavioural mechanisms.

The physiologic view is based on the hypothesis that social support influences the pathogenesis of disease through a direct effect on the affective state and the activity of the neuroendocrine system and the autonomic nervous system. Activation of the neuroendocrine system by negative emotions such as depression and stressful events can produce cardiac events or sudden death, especially in the vulnerable HF patient. Social support and social integration are presumed to provide a generalized positive affect that suppresses the neuroendocrine response. [8] Adequate social support may protect patients from the pathogenic influence of

stress. Patients with adequate supportive relationships perceive stressful events as less threatening, and thus negative affect is avoided and the neuroendocrine system will not be activated.

The behavioural model proposes that social support has its impact through an influence on health behaviours. Social relationships may facilitate or promote health behaviours such as not-smoking, adequate nutrition, regulated alcohol intake and exercise. Patients with HF who have adequate social support may be more successful in adhering to the prescribed medication regimen or to the dietary and fluid restrictions. Conversely, socially isolated HF patients may have difficulty altering their behavioural patterns which makes them more vulnerable to repeated readmissions and death.

Methods

In HF patients, a number of outcomes have been studied, but the following have received the maximum attention recently: readmission, mortality, QoL and depression. The impact of social support on these outcomes is reviewed in this article.

A computerized literature search in Medline, CINAHL and PsychLit was undertaken on each of the different outcomes in relation to social support. The key-word combinations 'heart failure' and 'social support, partner, spouse, married, couples' were combined with 'readmission or rehospitalization or hospital-admission', 'mortality or survival or prognosis', 'quality of life', and 'depression'. This search covers the period 1993 to 2003 in which most of the research in the field of HF emerged. Earlier research was taken into account when it was judged by the authors to be of particular interest. Furthermore, articles were identified through the examination of reference lists from included articles. The search was primarily aimed at HF populations but since this literature was sparse a broader perspective including myocardial infarction (MI) and cardiovascular disease was sometimes necessary.

In total, we found 17 studies that investigated the relationship between social support and different outcome measures in HF: 7 studies on social support and readmission, 4 studies on social support and mortality, 3 studies on social support and QoL and 3 studies on social support and depression. Because of the limited number of studies, we included all studies in this review.

Results

Readmission

Several studies have been done on factors that influence hospital readmissions in HF patients[14]: 7 studies included a measure of social support and 3 found a clear relationship between lack of social support and readmission rates. [14-16] Another

3 studies found descriptive evidence of a relationship. [17-19] One of the studies demonstrated that social support did not predict HF hospitalization. [20]

Vinson et al. [18] prospectively evaluated 161 patients with the primary diagnosis of HF admitted for an excacerbation of their illness; 47% were readmitted within 90 days of discharge from the index hospitalization. More than half (53%) of these readmissions were judged to be possibly preventable. A failing support system appeared to be the most important factor of influence in this respect.

Chin and Goldman [14] prospectively followed 257 HF patients during a 2-year period to identify predictors of readmission and death. Within 60 days after the initial admission, 32% of the patients either died or were readmitted. Single marital status, as an indicator of social support, was a significant predictor of hospital readmission, even after controlling for other medical risk factors.

Happ et al. [17] retrospectively studied the research files of 16 HF patients, who had participated in a clinical trial on the effect of transitional care: comprehensive discharge planning and home care follow-up, in order to identify and describe factors contributing to rehospitalization and prevention of rehospitalization. Eight rehospitalized patients and 8 patients who were not rehospitalized during the 6-month follow-up were purposely selected from the intervention group. By reviewing the medical records, 3 major risk factors for rehospitalization emerged: medication supply, dietary nonadherence and poor health behaviours. In addition, supportive family or friends and individual motivation were identified as factors that may have prevented rehospitalization.

Krumholz et al. [15] followed 292 patients with HF after hospitalization for HF. Social support was measured by 2 single-item questions. Patients were asked whether they could count on anyone to provide them with 1) emotional support and 2) with instrumental support. The absence of emotional support was an important predictor of cardiovascular events in the year after the initial hospital admission for HF. However, in a multiple regression that included gender as one of the covariates, this association between lack of emotional support and cardiovascular events was restricted to women.

Schwarz et al. [16] investigated patient factors and caregiver factors and their potential to influence hospital readmissions in HF patients. Patients and their caregivers (128 dyads) were followed for 3 months after hospital discharge; 56 (44%) HF-patients were readmitted within this 3-month period. The patient's severity of cardiac illness and functional health status predicted hospital readmission. Demonstrating the importance of social support, informal support of the caregiver reduced the risk of hospital readmission whereas high levels of stress and depression among caregivers increased the risk of hospital readmission.

Wright et al. [19] investigated factors influencing the length of hospital stay, and demonstrated that the presence of social problems and living alone were related to a longer-than-average length of hospital stay.

In contrast to the studies described above, Bennett et al. [20] found that social support did not predict HF hospitalization. The social support of 62 HF patients was assessed in relation to rehospitalization during a 6-month period. In this

follow-up period 23 patients (37%) were hospitalized. The investigators suggested that the missing relationship between social support and rehospitalization may be due to the fact that 73% of the patients were married and that overall (considering the mean score on the social support scale), patients believed they had support available most of the time (table 1).

Mortality

Several studies on patients with cardiac diseases indicate that poor social support is significantly associated with an increased risk of mortality, [9,10,21] but the prognostic importance of social support an patients with HF has received relatively little attention. We found 4 studies investigating the relationship between (the quality of) social support and mortality on patients with HF. In these 4 investigations, indicators of lack of social support or poor quality of social support predicted future mortality.

Chin and Goldman [14] reported that single marital status was an independent predictor of death in 257 HF patients during a 2-year follow-up period.

Coyne [22] went one step further and investigated the influence of marital quality on patient survival. Marital quality was obtained by interview and observational measures in 189 patients with HF and their spouses. High marital quality contributed significantly to patient survival during a 4-year follow up period. Social support was especially crucial to the survival of women.

Krumholz et al. [15] demonstrated that the absence of someone to provide emotional support was a strong, independent predictor of the occurrence of fatal and nonfatal cardiovascular events in the year after admission in 292 HF patients.

More recently, the study of Murberg et al. [23] evaluated the effects of social relationships on mortality risk and demonstrated an association between social isolation and mortality in 119 HF patients in a 2-year follow-up period. Social isolation was defined as the perception of patients' being unable to maintain social contact with family and friends. A marginally significant association was found between the intimate network support from a spouse, and mortality. The investigators cautiously state that this may indicate that for HF patients, lack of social support from a spouse may be more critical than lack of social support from others (table 2).

Quality of Life

With regard to the relationship between social support and QoL on patients with HF, 3 studies with conflicting results were found.

In a descriptive pilot study among women with HF, Bennett et al. [24] examined the relationships between symptom impact, perceived health status, perceived social support and overall QoL. Perceived social support was significantly, though not strongly, correlated with physical symptom impact as measured by the Minnesota Living with Heart Failure Questionnaire. Greater symptom impact was correlated with poorer health status.

Table 1. Social support and readmission

Study	Design	Population
Vinson et al. (1990) [18]	Prospective,	Hospitalized HF patients
	descriptive	(n=161, > 70 years)
		Follow-up 90 days
Chin and Goldman (1997) [14]	Prospective,	Hospitalized HF patients
	correlational	(n=257, 62%< 70 years)
		Follow-up 60 days
Happ et al. (1997) [17]	Retrospective,	Hospitalized HF patients
	descriptive	(n=12, 70-82 years)
		Follow-up 6 months
Krumholz et al. (1998) [15]	Longitudinal,	Hospitalized HF patients
	cohort-study	(n=292, > 65 years)
		Follow-up 1 year
Schwarz and Elman (2003) [16]	Prospective,	HF patients and their caregivers
	descriptive,	7-10 days after discharge (n=128,
	predictive	mean age patients 77 years,
		mean age caregivers 65 years)
		Follow-up 3 months
Bennett et al. (1997) [20]	Prospective,	Hospitalized HF patients
	cross-sectional	(n=62), mostly men
	cohort-study	NYHA I-IV
		Follow-up 6 months
Wright et al. (2001) [19]	Prospective,	Hospitalized HF patients
	descriptive,	(n=179, mean age 73 years)
	correlational	NYHA III-IV

Measurement	Results
Chart-review and patient interview	47% was readmitted in 90 days
	53% was preventable
	21% caused by inadequate social support
Chart review and patient interview	Single marital status is a risk factor for
	readmission (or death)
Social support; marital status	
Patient questionnaires, patient interview,	Factors contributing to rehospitalization;
chart review	medication supply, dietary nonadherence
	and poor health behaviours
	Factors contributing to prevention of
	rehospitalization; social support and
	individual motivation
Chart review and patient interview	For women emotional support was a
	independent predictor of cardiovascular
Social support; two single-item questions	events (fatal/non-fatal)
on emotional and instrumental support	
Chart review, patient questionnaires	Patient factors;
and patient interview	interaction between severity of cardiac
	illness and functional status predicted
Social support; Modified Inventory	readmission
of Socially Supportive Behaviors Scale	Caregiver factors
	Interaction between caregiver depression
	and stress, and informal social support
	predicted readmission
Chart review and patient questionnaires	No differences in social support between
	hospitalized and non-hospitalized patients
Social support: MOS Social Support Survey	
Chart review on socio-demographic,	Social problems requiring in-hospital
clinical characteristics, treatment-related	assessment and living alone were associated
factors and in-hospital progress	with longer hospital stay

Table 2. Social support and mortality

Study	Design	Population
Krumholz et al. (1998) [15]	Longitudinal,	Hospitalized HF patients
	cohort-study	(n=292, > 65 years)
		Follow-up 1 year
Chin and Goldman (1997) [14]	Prospective,	Hospitalized HF patients
	correlational	(n=257, 62%< 70 years)
		Follow-up 60 days
Coyne et al. (2001) [22]	Prospective,	HF patients and spouses at home
	predictive	(n=189, ± 53 years, 79% male)
		Follow-up 4 years
Murberg and Bru (2001) [23]	Prospective,	HF patients from an out-patient
	correlational	hospital practice
		(n=119, ± 66 years, 71% male)
		Follow-up 24 months

Table 3. Social support and quality of life

Study	Design	Population
Bennett et al. (1998) [24]	Descriptive,	Hospitalized women with HF
	correlational	(n=30, mean age 60 years)
Bennett et al. (2001) [25]	Prospective	Hospitalized HF patients
		(n=227, mean age 64 years)
		Follow up 12 months
Westlake et al. (2002) [26]	Descriptive,	Hospitalized HF patients
	correlational	awaiting heart transplantation
		(n=61, mean age 57 years)

Measurement	Results
Chart review and patient interview	For women emotional support was a strong, independent predictor of cardiovascular events (fatal/non-fatal)
Social support; two single-item questions on emotional and instrumental support	
Chart review and patient interview	Single marital status is a risk factor for (readmission or) death in patients with HF
Social support; marital status	
Patient observation, patient interview and chart review	Marital quality predicted 4-year survival in patients with HF
Marital Satisfaction	
Marital Routines	
Patient questionnaires and chart review	Social isolation was a significant predictor of mortality
Social support:	
Perceived Social Support and	
Perceived Social Isolation	

Measurement	Results
Patient questionnaires	Perceived social support was significantly,though not strongly, correlated with physical symptom impact measured by the MLHFQ.
Social support: MOS Social Support Survey	
Patient questionnaires and chart review	Changes in social support were significant predictors of changes in HRQoL; increase of social support increased HRQoL.
Social support: Social Support Survey	
Chart review, patient questionnaires and 6-minute walk test	No significant relationship between social status, social network, social support and HRQoL
Social support: MOS Social Support Survey	

Table 4. Social support and depression

Study	Design	Population
Frasure-Smith et al. (2000) [32]	Prospective, correlational	Hospitalized MI-patients (n=887, mean age 59 years) Follow-up 1 year
Holahan et al. (1995) [33]	Prospective, correlational	Late-middle-aged elderly with Cardiac Illness (n=615, 55-65 years) Follow-up 1 year
Murberg et al. (1998) [34]	Descriptive, correlational	HF patients from an out-patient hospital practice (n=119, ± 66 years, 71% male) Follow-up 24 months
Koenig (1998) [29]	Prospective, correlational	Hospitalized patients with HF, other cardiac diseases and other medical diseases (n= 342, >60 years) Follow-up 47 wk

Measurement	Results
Patient questionnaires and interview	Social support was not directly related to survival, but high levels of social support buffer the impact of depression on mortality and high levels of social support predict improvements in depressive symptoms.
Social support:	
Perceived Social Support Scale	
Number of close friends and relatives	
Marital status/Living alone	
Patient questionnaires	Individuals with acute and chronic cardiac illness reported more depressive symptoms compared to healthy controls at 1-year follow-up Social support showed a direct relationship to subsequent depressive symptoms as well as an indirect relationship mediated by adaptive coping
Social support:	
Life Stressors and Social Resources Inventory (LISRES)	
Physical examination (clinical variables) and patient questionnaires	Poor intimate network (spouses), social disability and neuroticism were significantly positively related with depression
Social support:	
Social network support	
Social disability	
Chart review and patient interview including psychiatric evaluation	Depression was identified in 36.5% of HF patients Social support predicted faster remission

In another study among both men and women with HF, the same investigative group [25] found that social support, assessed at baseline during a hospitalization for HF, did not predict 12-month health-related quality of life (HRQoL). Changes in social support significantly predicted changes in HRQoL, meaning that an increase of social support improves HRQoL.

Westlake et al. [26] also conducted a study to determine the influence of different variables on HRQoL in a population of 61 patients undergoing heart transplantation evaluation. No relationship was found between social network or social support and HRQoL in this sample. The investigators suggest that the lack of evidence may be partially explained in this sample by the lack of variability in social support within the sample (table 3).

Depression

The prevalence of depression in patients with HF is relatively high. In hospitalized patients, depression occurs in 14-36.5% of the patients. [27-29] In outpatient settings, the prevalence of depression is even higher, up to 42%. [30]

Given the impact of depression in HF partners, [31] it is important to determine factors related to depression. In doing so, we may uncover targets for intervention. Research by Frasure-Smith et al. [32] in MI-patients suggests that social support may be of importance in predicting and possibly preventing cardiac mortality related to depression. They found that the relationship between depression and cardiac mortality decreases with increasing social support. It is likely that the relationship found among patients with MI extends to those with HF.

Holahan et al. [33] focused on the protective role of social support and adaptive coping strategies in HF patients. Looking at determinants of depressive symptoms, they found that both social support and adaptive coping were significantly related to depressive symptoms at follow-up. Social support was also significantly related to adaptive coping. That is, social support was directly related to subsequent depressive symptoms and indirectly mediated by adaptive coping strategies.

Murberg et al. [34] assessed a sample of 119 clinically stable HF patients on the role of social support and social disability as predictors of depression. Poor intimate network support (spouse support) was directly and negatively associated with depression. Social disability, as a result of living with HF, was significantly associated with depression.

Koenig [29] found that among hospitalized HF patients, major depression was identified in 36.5% of the patients. High social support predicted faster remission of a major depression (table 4).

Discussion

Psychological factors are increasingly recognized as important in studying effects of treatment in patients with HF. Research on the influence of psychosocial factors on outcomes in patients with cardiovascular diseases shows an independent and presumably strong relationship between social support and health outcomes. The studies reviewed suggest that a similar relationship applies in HF patients.

Social support appears to be a strong predictor of hospital readmissions and mortality in HF patients. Especially emotional support, probably support provided by partners or spouses, seems to play an important role. Some studies show that support is also related to the prevalence of depression and with remission of a major depression in HF patients. Surprisingly, there is less evidence to support a relationship between social support and QoL.

Some restraints on these findings are necessary. First, research on the impact of social support in HF patients is sparse. There are simply not enough well-conducted studies with sufficient sample sizes to allow us to come to concrete conclusions. This is confirmed by McMahon et al. [35] who found in their overview of research on the effects of psychosocial factors (depression, anxiety, coping-style and social support) in HF, only 2 studies on social support that met the inclusion criteria.

Second, the available evidence is conflicting, with some investigators finding no relationship between social support and outcomes, while others demonstrated strong, independent relationships. This discrepancy may be related to the multiple and divergent ways in which the concept of social support has been operationalized. Some studies simply conceptualize social support as living alone or not, a state that may or may not indicate lack of available social support. In other studies, social support is conceptualized as having a partner or spouse, yet it is well known that many individuals with a partner or spouse perceive that they receive no social support from that person. Others have measured social support as the perception of the individual on whether they have adequate social, emotional, or instrumental support.

Given the potential importance of social support to outcomes in HF patients, future research in this area should concentrate on clarifying the relationship between social support and outcomes by first carefully considering the definition of social support and including a measure that truly taps this concept.

In cardiovascular disease, most psychosocial interventions are aimed at the patient; spouses or partners are rarely involved. [36] In an extended review on social support interventions, Hogan et al. [37] concluded that although studies on social support interventions produce encouraging results, the same conceptual and methodological problems described above occurred in these studies and limited the ability to make recommendations for clinical practice based on these findings. Recently some efforts have been made to develop and investigate intervention programs to improve or enhance social support in patients with HF. [38,39] These pioneering studies are aiming to improve lifestyle changes of patiënt with HF by enhancing social support.

Because so little research on social support in HF patients has been done, many questions remain unanswered. What are specific characteristics of HF patients in relation to the need for support? How can this support best be provided? Which support interventions are suitable in HF patients and their caregivers?

Spouses seem to play an essential role in providing support and in doing so in preventing readmissions. Therefore, this support resource needs more study. Since providing care for a HF patient proves to be stressful and burdensome, [40] it may also be necessary to investigate the needs of caregivers too.

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References

1 Remme WJ, Swedberg K. Guidelines for the diagnosis and treatment of chronic heart failure. *Eur Heart J* 2001; 22:1527-60.

2 Cowie MR, Fox KF, Wood DA, Metcalfe C, Thompson SG, Coats AJ et al. Hospitalization of patients with heart failure: a population-based study. *Eur Heart J* 2002; 23:877-85.

3 Mosterd A, Hoes AW. Reducing hospitalizations for heart failure. *Eur Heart J* 2002; 23:842-45.

4 Jaarsma T, Halfens R, Tan F, Abu-Saad HH, Dracup K, Diederiks J. Self-care and quality of life in patients with advanced heart failure: the effect of a supportive educational intervention. *Heart Lung* 2000; 29:319-30.

5 McAlister FA, Lawson FM, Teo KK, Armstrong PW. A systematic review of randomized trials of disease management programs in heart failure. *Am J Med* 2001; 110:378-84.

6 Berkman LF. The role of social relations in health promotion. *Psychosom Med* 1995; 57:245-54.

7 Reifman A. Social relationships, recovery from illness, and survival: A literature review. *Ann Behav Med* 1995; 17:124-31.

8 Cohen S. Psychosocial models of the role of social support in the etiology of physical disease. *Health Psychol* 1988; 7:269-97.

9 Berkman LF, Leo-Summers L, Horwitz RI. Emotional support and survival after myocardial infarction. A prospective, population-based study of the elderly. *Ann Intern Med* 1992; 117:1003-9.

10 Case RB, Moss AJ, Case N, McDermott M, Eberly S. Living alone after myocardial infarction. Impact on prognosis. *JAMA* 1992; 267:515-19.

11 Riegel B. Social support and psychological adjustment to chronic coronary heart disease: operationalization of Johnson's behavioral system model. *ANS Adv Nurs Sci* 1989; 11:74-84.

12 House JS, Umberson D, Landis KR. Structures and processes of social support. *Annual review of Sociology* 14, 293-318. 1988.

13 Cantor M. Neighbours and friends. *Research on Aging* 1979; 1:434-63.

14 Chin MH, Goldman L. Correlates of early hospital readmission or death in patients with congestive heart failure. *Am J Cardiol* 1997; 79:1640-44.

15 Krumholz HM, Butler J, Miller J, Vaccarino V, Williams CS, Mendes de Leon CF, Seeman TE, Kasl VS, Berkman LF. Prognostic importance of emotional support for elderly patients hospitalized with heart failure. *Circulation* 1998; 97:958-64.

16 Schwarz KA, Elman CS. Identification of factors predictive of hospital readmissions for patients with heart failure. *Heart Lung* 2003; 32:88-99.

17 Happ MB, Naylor MD, Roe-Prior P. Factors contributing to rehospitalization of elderly patients with heart failure. *J Cardiovasc Nurs* 1997; 11:75-84.

18 Vinson JM, Rich MW, Sperry JC, Shah AS, McNamara T. Early readmission of elderly patients with congestive heart failure. *J Am Geriatr Soc* 1990; 38:1290-95.

19 Wright SP, Verouhis D, Gamble G, Swedberg K, Sharpe N, Doughty RN. Factors influencing the length of hospital stay of patients with heart failure. *Eur J Heart Fail* 2003; 5:201-09.

20 Bennett SJ, Pressler ML, Hays L, Firestine LA, Huster GA. Psychosocial variables and hospitalization in persons with chronic heart failure. *Prog Cardiovasc Nurs* 1997; 12:4-11.
21 Ruberman W, Weinblatt E, Goldberg JD, Chaudhary BS. Psychosocial influences on mortality after myocardial infarction. *N Engl J Med* 1984; 311:552-59.
22 Coyne JC, Rohrbaugh MJ, Shoham V, Sonnega JS, Nicklas JM, Cranford JA. Prognostic importance of marital quality for survival of congestive heart failure. *Am J Cardiol* 2001; 88:526-29.
23 Murberg TA, Bru E. Social relationships and mortality in patients with congestive heart failure. *J Psychosom Res* 2001; 51:521-27.
24 Bennett SJ, Baker SL, Huster GA. Quality of life in women with heart failure. *Health Care Women Int* 1998; 19:217-29.
25 Bennett SJ, Perkins SM, Lane KA, Deer M, Brater DC, Murray MD. Social support and health-related quality of life in chronic heart failure patients. *Qual Life Res* 2001; 10:671-82.
26 Westlake C, Dracup K, Creaser J, Livingston N, Heywood JT, Huiskes BL, Fonarow G, Hamilton M. Correlates of health-related quality of life in patients with heart failure. *Heart Lung* 2002; 31:85-93.
27 Freedland KE, Rich MW, Skala JA, Carney RM, Davila-Roman VG, Jaffe AS. Prevalence of depression in hospitalized patients with congestive heart failure. *Psychosom Med* 2003; 65:119-28.
28 Jiang W, Alexander J, Christopher E, Kuchibhatla M, Gaulden LH, Cuffe MS, Blazing MA, Davenport C, Califf RM, Krishnan RR, O'Connor CM. Relationship of depression to increased risk of mortality and rehospitalization in patients with congestive heart failure. *Arch Intern Med* 2001; 161:1849-56.
29 Koenig HG. Depression in hospitalized older patients with congestive heart failure. *Gen Hosp Psychiatry* 1998; 20:29-43.
30 Skotzko CE, Krichten C, Zietowski G, Alves L, Freudenberger R, Robinson S, Fisher M, Gottlieb SS. Depression is common and precludes accurate assessment of functional status in elderly patients with congestive heart failure. *J Card Fail* 2000; 6:300-5.
31 Murberg TA, Bru E, Svebak S, Tveteras R, Aarsland T. Depressed mood and subjective health symptoms as predictors of mortality in patients with congestive heart failure: a two-years follow- up study. *Int J Psychiatry Med* 1999; 29:311-26.
32 Frasure-Smith N, Lesperance F, Gravel G, Masson A, Juneau M, Talajic M, Bourassa MG. Social support, depression, and mortality during the first year after myocardial infarction. *Circulation* 2000; 101:1919-24.
33 Holahan CJ, Moos RH, Holahan CK, Brennan PL. Social support, coping, and depressive symptoms in a late-middle-aged sample of patients reporting cardiac illness. *Health Psychol* 1995; 14:152-63.
34 Murberg TA, Bru E, Aarsland T, Svebak S. Social support, social disability and their role as predictors of depression among patients with congestive heart failure. *Scand J Soc Med* 1998; 26:87-95.
35 MacMahon KM, Lip GY. Psychological factors in heart failure: a review of the literature. *Arch Intern Med* 2002; 162:509-16.
36 Linden W. Review: no definite conclusions can be drawn as to the effect of psychological factors in congestive heart failure. *Evid Based Ment Health* 2002; 5:124.

37 Hogan BE, Linden W, Najarian B. Social support interventions. Do they work? *Clinical Psychology Review* 2002; 22:381-440.
38 Daugherty J, Saarmann L, Riegel B, Sornborger K, Moser D. Can we talk? Developing a social support nursing intervention for couples. *Clin Nurse Spec* 2002; 16:211-18.
39 Riegel B, Carlson B. Is individual peer support a promising intervention for persons with heart failure? *J Cardiovasc Nurs* 2004; 19:174-83.
40 Karmilovich SE. Burden and Stress Associated with Spousal Caregiving for Individuals with Heart Failure. *Prog Cardiovasc Nurs* 1994; 9:33-8.

Marital Status, Quality of Life and Clinical Outcome in Patients with Heart Failure

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Abstract

Aim

This study investigated the impact of having a partner on Quality of Life (QoL), the number of hospital readmissions, and 9-month survival in patients with heart failure (HF).

Methods

The study population consisted of hospitalized HF patients. QoL was measured by the Cantril Ladder of Life (0-10) during hospital admission. Clinical data, readmission rate and number of deaths were registered by patient interview and chart review.

Results

Of the 179 patients, 96 (54%) were married or were living with a partner. Differences in QoL between married patients and those living alone were most pronounced with regard to future expectations of QoL (6.5 vs. 5.0, p=0.00). However, in a multivariate model QoL was primarily associated with socioeconomic status, age and gender. Married patients had 12% less events in the 9-month follow-up period compared to patients living alone (p=not significant).

Conclusion

This study indicates that most HF patients who are living alone are mostly elderly women with a low socioeconomic status, who are at risk for recurrent events and a worse QoL.

Introduction

Heart Failure (HF) is a chronic and debilitating condition, that seriously affects the lives of patients and their families. Despite advances in medical treatment HF is still associated with high morbidity and mortality, high hospitalization rates, and impaired Quality of Life (QoL).[1-3] The current treatment of HF is complex and requires permanent life style changes. To cope with and adjust to the complex regimen of these life style prescriptions, patients need support from health care providers and from their relatives.[4] There is substantial evidence demonstrating the association between the lack of social support and poor health outcomes in general populations as well as in patients with cardiovascular disease.[5,6]

Studies concerning the association between marital status and QoL in patients with HF as an outcome parameter, apparently could not be found. Although one might expect such a relationship, no prospective data are available in HF patients.

Previous research on the impact of marital status, as a measure of social support, on outcomes in patients after a myocardial infarction (MI) or patients with HF showed conflicting results. Some authors[7,8] found strong independent relationships between marital status and mortality in patients with HF and in patients after an MI. Others found that although there was a difference in outcomes between patients living alone and patients not living alone, marital status was not an independent risk factor for mortality in MI patients.[9] They concluded that advanced age, and not social support, seemed largely responsible for the increased mortality in patients living alone.

After reviewing these controversies we investigated the impact of marital status on QoL, the number of all cause hospital readmissions and survival during a 9 month follow-up period. The following research question was formulated:

Are there differences in self-reported QoL, the number of readmissions and 9-month survival between married HF patients (or living with a partner) and HF patients living alone?

Methods

Patients

A secondary analyses was performed on patients who participated in the study of Jaarsma et al.[10] on the effect of education and support on QoL in patients with HF. Patients in this study were included during hospital admission on a cardiology ward of a University Hospital in the Netherlands between March 1994 to March 1997. Patients were eligible for the study if they had symptoms of HF for 3 months or longer, had been classified by the attending physician as New York Heart Association (NYHA) Class III or IV, were over 50 years of age and were literate in Dutch. Patients were excluded from the study if they had a co-existing, severe,

chronic debilitating and life-threatening disease (e.g. cancer); if they resided in, or planned to be discharged to a nursing home or if they had a psychiatric diagnosis. Patients who had had a Coronary Artery Bypass Graft (CABG), Percutanous Transluminal Coronary Angioplasty (PTCA) or valve replacement in the last 6 months or were expected to have such a treatment within 3 months were also excluded from the study. Patients with systolic and diastolic dysfunction were included.

The study conformed with the principles outlined in the declaration of Helsinki and was approved by the hospital ethics committee.

Once informed consent was obtained, patients were randomly assigned to receive care as usual or a supportive-educative nursing intervention. Since care as usual patients and intervention group patients were equally present in our subgroups of patients (either living with a partner or living alone, table 1), the original study design did not interfere with our research question.

Measures

Marital status was assessed by structured interview. In the analysis, HF patients who were living with a partner in the same household (either married or not married) were compared with patients with HF who were living alone (divorced/widowed or single).

Socioeconomic status (SES) was assessed by means of the patient's occupation or former occupation. The classification is based on the following consideration: scholinglevels, blue or white collar work, self-employed or not, and, if applicable, size of the business.

QoL was measured during admission by the Cantril Ladder of Life. [11] This instrument has been used in various cardiovascular studies and is considered to be a valid measure of 'global well-being'. [12-14] It does not cover QoL as a multi dimensional concept, but it is related to aspects of QoL such as psychosocial adjustment and functional capabilities. [15] Patients were asked to rate their sense of well-being on a scale from 0-10 (10 reflecting the best and 0 reflecting the worst possible life). They were asked to do so with regard to the time of interview (during hospital admission, after being treated and stabilized), with regard to the month prior to hospital admission and with regard to their expectation of well-being for 3 years in the future.

Hospital readmissions (all causes) were assessed by follow-up interviews with the patient at 1, 3, and 9 months. All interviews were carried out by independent interviewers at home using standardized questionnaires. Additional information on readmissions, reasons for readmission and cause of death were obtained from the hospital computer database and from the patient's medical record.

A constellation of variables known from the literature that would be potentially important in predicting clinical outcome and QoL in HF patients were identified. These included demographic factors (age, sex and socioeconomic status); medical history (duration of heart failure, cause and comorbidities); admission characteristics (left ventricular ejection fraction (LVEF) and NYHA classification)

and discharge laboratory tests (creatinine). These data were collected from the patient's medical chart and patient interview.

Analysis

All data were entered into an SPSS database and analysed using descriptive statistics, parametric (Student t-test) and non-parametric tests (chi-square and Mann Whitney test) and multivariate regression analysis.

Data of 179 participating HF patients were analysed, to investigate differences between patients living with a partner and patients living alone. Differences between patients living with a partner and those living alone, with regard to QoL, number of all cause readmissions and 9-month survival, were evaluated univariately. In addition, differences in outcome variables for the levels of relevant covariates were evaluated. All significant covariates at a level of $p<0.10$ were entered in a stepwise multivariate analysis (backward elimination) to establish independent determinants of clinical outcome and QoL.

Table 1. Demographic and clinical data of HF patients by marital status

Patient characteristics		Total (n=179)	Married (n=96)	Living alone (n=83)	P-value
Demographic variables					
Age (yr)		73 (±9)	70 (±8.3)	77 (±8.1)	0.00
Gender	male	57%	80%	31%	0.00
Socioeconomic status	high	32%	40%	22%	0.01
Randomization					
Number of patients in intervention group		84 (47%)	45 (47%)	39 (47%)	0.99
Number of patients in care as usual group		95 (53%)	51 (53%)	44 (53%)	
Clinical variables					
LVEF		34% (±13)	32% (±12)	37% (±14)	0.03
NYHA III		17%	21%	13%	0.77
III-IV		21%	23%	18%	
IV		62%	55%	69%	
Length of heart disease (months)		108 (±95)	116 (±97)	100 (±91)	0.23
Number of previous HF hospital admissions		3.3 (±2.5)	3.5 (±2.5)	3.1 (±2.4)	0.18
Number of symptoms		4.0 (±1.5)	3.9 (±1.6)	4.0 (±1.4)	0.98
Cause	Ischemic	52%	53%	51%	0.74
	Non-ischemic	48%	48%	45%	
Number of comorbidities		1.2 (±0.9)	1.2 (±0.96)	1.2 (±0.81)	0.54
Diabetes	yes	30%	30%	30%	0.99
Lungdisease	yes	23%	26%	20%	0.38
Creatinine level (µmol/L) at discharge		141`(±69)	140 (±67)	143 (±71)	0.91

Results

Study population

The study population consisted of 179 HF patients. The mean age was 73 years and 57% of the patients was male. Ninety-six patients (54%) were married or living with a partner, and eighty-three (46%) were living alone. HF patients living with a partner were significantly younger (70 vs. 77 years), more often male (80% vs 31%), had a lower LVEF (32% vs. 37%) and a higher SES (40% vs. 22%) (table 1).

Quality of Life

The overall QoL scores in this population of HF patients were low, ranging from 4.6 to 6.4. The scores represent the impact of a period of deterioration leading to a hospital admission in which treatment leads to stabilization and recovery. This process can be recognized in the QoL scores. The mean QoL score regarding the month before hospital admission was 4.6 (sd 2.6). During hospitalization, after the patients were treated and stabilized, the mean QoL score recovered to 6.4 (sd 2.6). Recovery did not automatically translate into higher expectations for the future: we found a mean score of 5.8 (sd 2.3). It must be noted that the construct of 'QoL for 3 years in the future' proved to be a difficult concept for patients, considering the number of missing data (48%) on this variable (table 2).

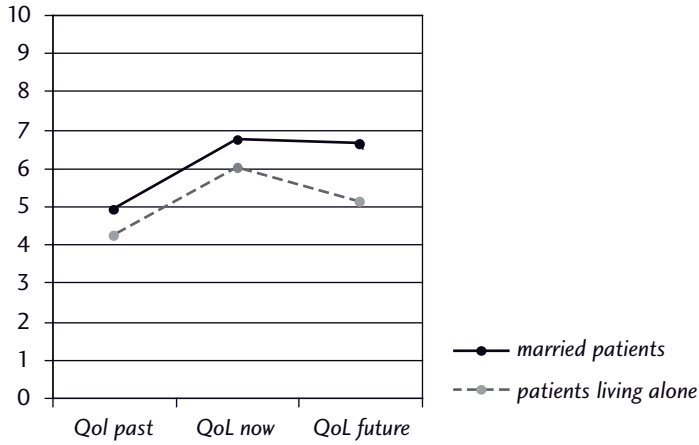
Table 2. Mean scores and differences on outcome variables of HF patients by marital status

	Total	Married patients	Patients living alone	p-value
QoL now (n=168)	6.4 (±2.2)	6.7 (±2.2)	6.0 (±2.2)	0.05
QoL past (n= 159)	4.6 (±2.7)	4.9 (±2.8)	4.2 (±2.6)	0.11
QoL future (n= 93)	5.9 (±2.4)	6.6 (±2.2)	5.1 (±2.4)	0.00

The QoL scores of patients living alone were consistently lower than the QoL scores of patients living with a partner. Patients living with a partner reported a higher QoL score during hospital admission (6.7 vs. 6.0, p=0.05), with regard to the month before to hospital admission (4.9 vs. 4.2, p=0.11) and especially with regard to expectations on QoL in the future (6.5 vs. 5.0, p=0.00) (figure 1)

A multiple regression analysis was performed with QoL as the dependent variable and age, gender, SES, LVEF and marital status as the independent variables. No interaction effects were found between marital status and SES, age and gender. Multivariate analysis showed that although univariate there was a difference between HF patients living with a partner and HF patients living alone, according to the multivariate model QoL was primarily associated with other factors. The QoL of HF patients during hospital admission was significantly associated with SES (r=0.24, p=0.00) and age (r=-0.14, p=0.07). Expectations on QoL for 3 years in the future was significantly associated with age (r=-0.30, p=0.02) and gender (r=-0,24, p=0.00).

Figure 1. QoL scores by marital status



Readmission and survival

A total of 103 HF patients experienced an event (readmission or death) in the 9-month follow-up period. Of those who lived with a partner, 50 (52%) patients had an event compared to 53 (64%) patients who were living alone. The group of patients living with a partner accounted for 37 readmissions and 19 deaths whereas patients living alone accounted for 41 readmissions and also 19 deaths. There was a difference of 12% less events in patients who lived with a partner, this difference was not statistically significant (p=0.11) (table 3).

Table 3. Mean event rate and differences by marital status

	Total (n=179)	**Married patients (n=96)**	**Patients living alone (n=83)**	**p-value**
Number of patients with an event (readmission or death)	103	50 (52%)	53 (64%)	0.11
Number of patients with readmission(s)(all causes)	78	37 (38%)	41 (49%)	0.14
Number of patients who died (all causes)	38	19 (20%)	19 (23%)	0.56

Discussion

This study investigated the impact of marital status on Quality of Life (QoL), 'all cause' hospital readmission and mortality in HF patients.

QoL scores in our population of HF patients were low compared with the study of Ormel, [16] in which healthy, elderly Dutch people showed a mean score of 7.9 on the Cantril Ladder of Life. Our scores represent the impact of a period of deterioration leading to hospitalization. During hospitalization the effects of treatment are obviously translated into higher QoL scores.

By evaluating differences in QoL between the group of patients living with a partner and patients living alone, we initially found higher QoL scores in patients living with a partner compared with patients living alone. However, in a multivariate model the difference in QoL was explained by other factors such as socioeconomic status, age and gender, and not by marital status.

It is known that the QoL of patients with HF is severely affected. [2] Clearly, being married in itself does not guarantee a better QoL, other factors such as age, gender are important to consider as well.

The construct of expectations of QoL for the future remains interesting. The fact that almost half of the total population (48%) would not or could not answer this question is remarkable in itself and is probably related to the rather grim prognosis of HF patients. [17] In the remaining 52% of the patients we see that patients who are living alone, mostly eldery women, do have rather low expectations of their QoL in the future, significantly lower than the married group of patients who were younger and mostly male.

In our population of 179 HF patients we also investigated the number of events in a 9-month follow-up period after hospital admission. We found a difference of 12% less events in patients living with a partner compared with patients who were living alone. We consider this 12% difference as clinically relevant because of the serious impact of each hospital admission on HF patients and their social environment, and equally important because of the burden on the healthcare system and healthcare costs.

Although relevant, our results were not as strong as those reported by Chin and Goldman. [8] They found marital status to be a strong independent predictor of readmission or death. The difference may be attributible to differences in both study populations. Our population was older (73 vs. 67 yrs, respectively) and more patients had systolic dysfunction (LVEF 87% < .50 vs. 54% < .50, respectively). It is well known that advanced age and severity of systolic dysfunction are both strongly related to hospital readmission rates and mortality in HF patients. [1] These factors may have been stronger than the effect of marital support.

Another explanation may be that it is not marital status in itself that protects patients from events, but rather the quality of the relationship that contributes to better outcome. Recent research showed the prognostic importance of the quality of relationships in the onset and prognosis of cardiovascular disease. [18,19] Both studies also indicated that marital quality may be more crucial for women than for men.

Combining the low QoL scores in HF patients who are living alone with the trend towards more events in this group, we can conclude that we identified a group of patients, elderly women with a low socioeconomic status, who are vulnerable and probably need extra attention from health care providers.

Some limitations of our study must be considered. First of all we investigated the impact of having an intimate relationship as an important source of social support. We did not evaluate other sources of social support such as support of family members and friends, which may be important especially for HF patients who are living alone. Furthermore, the study population was limited by the small sample size and by the choice of instrument used to measure QoL. The concept of QoL is generally seen as multidimensional and subjective. Our instrument, the Cantril Ladder of Life, is measuring subjective 'global well-being' which does not cover the whole concept of QoL but is related to important aspects of QoL. Further research, in which more elaborated QoL measures are used, is needed to improve our understanding of the relationship between marital status and QoL.

Conclusion

It can be concluded that marital status seems to be associated with the number of events (hospital readmission and death) in patients with HF. Patients living with a partner had 12% less events in the 9-month follow-up period compared to patients living alone. Furthermore, HF patients living with a partner also had higher QoL scores. However, although we found differences in QoL and clinical outcome between married patients and patients living alone, marital status was not the primary predictor.

This study indicates that in a Dutch sample of HF patients, elderly women who live alone with low socioeconomic resources, are primarily at risk for recurrent events and worse QoL. In future research and practice it is necessary to focus not only on marital status, but on the quality of marital relationships and its impact on outcomes in patients with HF.

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References

1 Cowie MR, Fox KF, Wood DA, Metcalfe C, Thompson SG, Coats AJ, Poole-Wilson PA, Sutton GC. Hospitalization of patients with heart failure: a population-based study. *Eur Heart J* 2002; 23:877-885.

2 Juenger J, Schellberg D, Kraemer S, Haunstetter A, Zugck C, Herzog W, Haass M. Health related quality of life in patients with congestive heart failure: comparison with other chronic diseases and relation to functional variables. *Heart* 2002; 87:235-41.

3 Mosterd A, Hoes AW. Reducing hospitalizations for heart failure. *Eur Heart J* 2002; 23:842-45.

4 Riegel B. Social support and psychological adjustment to chronic heart disease: Operationalization of Johnson's behavioral system model. *Adv Nurs Sci* 1989; 11:74-84

5 Berkman LF. The role of social relations in health promotion. *Psychosom Med* 1995; 57:245-54.

6 Reifman A. Social relationships, recovery from illness, and survival: A literature review. *Ann Behav Med* 1995; 17:124-31.

7 Case RB, Moss AJ, Case N, McDermott M, Eberly S. Living alone after myocardial infarction. Impact on prognosis. *JAMA* 1992; 267:515-19.

8 Chin MH, Goldman L. Correlates of early hospital readmission or death in patients with congestive heart failure. *Am J Cardiol* 1997; 79:1640-44.

9 O'Shea JC, Wilcox RG, Skene AM, Stebbins AL, Granger CB, Armstrong PW, Bode C, Ardissino D, Emanuelsson H, Aylward PE, White HD, Sadowski Z, Topol EJ, Califf RM, Ohman EM. Comparison of outcomes of patients with myocardial infarction when living alone versus those not living alone. *Am J Cardiol* 2002; 90:1374-77.

10 Jaarsma T, Halfens R, Huijer Abu-Saad H, Dracup K, Gorgels T, van Ree J, et al. Effects of education and support on self-care and resource utilization in patients with heart failure. *Eur Heart J* 1999; 20:673-82.

11 Cantril H. The pattern of human concerns. New Brunswick: Rutgers University, 1965.

12 Jaarsma T, Kastermans MC. Recovery and quality of life one year after coronary artery bypass grafting. *Scand J Caring Sci* 1997; 11:67-72.

13 Senten CMS. The well-being of patients having CAB surgery: a test of Orem's self-care nursing theory. Maastricht: University of Maastricht, 1991.

14 Jenkins LS, Brodsky M, Schron E, Chung M, Rocco T Jr, Lader E, Constantine M, Sheppard R, Holmes D, Mateski D, Floden L, Prasun M, Greene HL, Shemanski L. Quality of life in atrial fibrillation: the Atrial Fibrillation Follow-up Investigation of Rhythm Management (AFFIRM) study. *Am Heart J* 2005; 149:112-20.

15 Jaarsma T, Halfens R, Abu-Saad HH, Dracup K, Stappers J, van Ree J. Quality of life in older patients with systolic and diastolic heart failure. *Eur J Heart Fail* 1999; 1:151-60.

16 Ormel J, Kempen GI, Deeg DJ, Brilman EI, van Sonderen E, Relyveld J. Functioning, well-being, and health perception in late middle-aged and older people: comparing the effects of depressive symptoms and chronic medical conditions. *J Am Geriatr Soc* 1998; 46:39-48.

17 McMurray JJV, Stewart S. The burden of heart failure. *Eur Heart J Suppl* 2003; D50-D58.

18 Coyne JC, Rohrbaugh MJ, Shoham V, Sonnega JS, Nicklas JM, Cranford JA. Prognostic importance of marital quality for survival of congestive heart failure. *Am J Cardiol* 2001; 88:526-29.

19 Gallo LC, Troxel WM, Kuller LH, Sutton-Tyrrell K, Edmundowicz D, Matthews KA. Marital status, marital quality, and atherosclerotic burden in postmenopausal women. *Psychosom Med* 2003; 65:952-62.

Patients:
the impact on the partner's life

Living with Heart Failure:
partner perspectives

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Abstract

Background

In order to preserve the supportive capabilities of partners of Heart Failure (HF) patients is it necessary to gain insight in the experiences and potential needs of these partners.

Methods

Thirteen partners of HF patients participated in semi-structured interviews that specifically focused on their experiences as a partner. Patients had had HF for at least 18 months and their partners were interviewed at home without the patient being present. Kwalitan 5.09 was used to analyse the qualitative data. Four independent researchers interpreted the data and discussed findings.

Results

Partners of HF patients experience several changes in life reflected in 4 main themes: changes in life, changes in relationship, coping and support. Partners support patients in their daily activities, they often change their own daily schedule and have to adjust their joint activities. Regaining a new balance together is one of the challenges that couples face when confronted with HF. Anxiety is an important theme especially in the acute phase sometimes interfering with adequate coping strategies. Changes in relationship are related to difficulties in communication and sexuality.

Conclusion

Although most partners seem to cope relatively well with the impact of HF on their lives, they are vulnerable especially at the onset of the disease. It seems important to involve partners actively in the process of rehabilitation and recognize their importance and their potential problems.

Background

Heart Failure (HF) is an increasingly prevalent, life-threatening condition with serious consequences in daily life. [1;2] Nearly 6.5 million people in Europe and 5 million people in the USA suffer from HF. [3] The course of the disease is characterized by many difficult issues like debilitating physical symptoms, role changes, and frequent hospitalizations. As a consequence, HF patients face many challenges in dealing with the condition and its treatment; they are forced to make lifestyle changes that affect their Quality of Life (QoL). Several studies in patients with advanced HF indicate significant emotional distress and poor QoL [4;5] as a result of the changes related to HF. Furthermore, there are studies that consistently demonstrate a strong association between poor emotional well-being and increased patient morbidity and mortality. [6-8]

In exploring factors that influence outcome in HF patients the role of partners and family is recognized to be essential in the progress of the disease. Studies indicate the positive impact of social support on patient outcome like mortality and re-hospitalization rates. [9] On the other hand caring for a patient with HF requires considerable effort and can affect the caregiver's health and well-being and increase stress and anxiety. (10-14) These adverse effects may contribute to physical morbidity and even to mortality in caregivers. [15-17]

Giving care to patients with HF is burdensome and stressful and the number of helping behaviours is significantly related to the level of perceived stress in partners. [12] Rohrbaugh et al. [14] found high levels of psychological distress in HF patients as well as in their partners and Luttik et al. [13] even found a tendency for the partner's QoL to be lower than the QoL of the HF patient. Recently, a few investigators have focussed on patients and their spouses as a couple. It is hypothesized that the experience of patients and their spouses are interrelated and that the way couples cope is an important influencing factor regarding patient outcome; the quality of the marital relationship appeared to be an independent predictor of mortality in HF patients. [18;19]

The health and well-being of partners is important to consider in order to preserve the supportive capability of the care giving partner, but all the more because research has indicated that the partner's level of mental health or emotional well-being is significantly associated with the emotional well-being [11;20] and psychological adjustment of patients. [21]

Most previous research on the situation of partners and family is based on quantitative, mostly general measures, measuring the level of well-being, QoL, caregiver burden or strain and is aimed at exploring predictors of well-being and burden. These quantitative methods do not provide inside in how HF affects the caregiver's lives and which aspects of the caregiving role are specifically influencing caregiver well-being and QoL. There are two studies that focus on the real experience of care giving partners. Martensson [22] explored factors that influence the ability of partners to give support to the HF

patient. He found that the active involvement of partners in the care for the HF patient is an important condition for partners to provide care. Recently, Aldred and colleagues [23] explored the impact of end-stage HF on the lives of patients and their carers by using a qualitative design. Although this study described to some extend the effects that HF had on the lives of partners, an important limitation may have been that partners were interviewed in presence of the patient which may have influenced their willingness to discuss their negative experiences.

Building on the existing knowledge, we conducted a study aimed at exploring the explicit experiences of partners of HF patients and on specific factors that influence caregiver well-being and QoL.

Methods

A qualitative study design was used by conducting semi-structured interviews with partners of HF patients at home, without patients being present. Data were collected from March to June, 2005. Participants were partners of a subset of patients that had participated in the Dutch NHF-COACH-trial on effects of advising and counselling in HF patients. [24] Within the COACH-trial 1049 HF patients were randomized into three groups; care as usual, basic support and intenseive support, with a follow-up period of 18 months.

Table 1. Patient and partner characteristics

Resp	Partners			Patients		
	Gender	Age (yrs)	Employment status	Gender	Age (yrs)	NYHA class*
1	Female	61	No	Male	68	-
2	Female	57	Yes	Male	60	II
3	Female	65	No	Male	67	II
4	Female	73	No	Male	74	II
5	Female	73	No	Male	79	II
6	Male	72	No	Female	76	II
7	Female	56	No	Male	59	-
8	Male	80	No	Female	76	II
9	Female	54	No	Male	65	II
10	Female	73	No	Male	75	II
11	Female	73	No	Male	71	II
12	Male	47	Yes	Female	46	II
13	Female	70	No	Male	70	III

**NYHA class = New York Heart Association, functional class*

I= no limitation of physical activity, II= slight limitation of physical activity,

III= marked limitation of physical activity, IV= unable to carry out physical activity without discomfort

A convenience sample of partners was invited to participate by telephone. The partner was defined as the person indicated by the patient to be his or her partner, either married or living together (not married) and residing in the patient's household. There were no specific in-or exclusion criteria except for the HF patient having completed the COACH-study and the partner to be willing to have an interview (with informed conseent of the HF patient). It was emphasized that the interview considered only the partner, not the patient. When positive, the interviewer contacted the partner to make an appointment.

Nineteen respondents were approached, thirteen agreed to participate. Reasons for refusal were; no interest (1), fear of family problems (1), availability not within data gathering time (1), patient had just undergone surgery (1), and reason unknown (2).

Ten women and three men were interviewed, their ages varied from 47 to 80 with a mean of 66 years. Two partners were employed and 11 partners had retired (table 1).

All patients had had HF for at least 18 months and were in a relatively stable condition. Partners were approached independent of randomisation group.

Data collection

The interviews were conducted at the participant's home, one participant preferred to come to the hospital. The interviews lasted 40 minutes on average and were tape-recorded with participant's prior permission.

The interview covered the following key issues; (1) introduction and assessment of demographics, (2) the course of the disease and the health status at the time of the interview, (3) changes in life, (4) impact of HF on the marital relationship, and (5) potential problems and needs.

After every second interview the contents were discussed with a member of the research team, in order to compare the data with previous results.

Data analysis

Data analysis was performed by following the process of content analysis [25,26]: (1) A full anonymous report of the interviews was typed out shortly after the interview had taken place. These transcripts were read thoroughly multiple times to get a good comprehension of the data. (2) The data was then imported into Kwalitan software version 5.09. The text files of the interview were segmented and coded in single words and short sentences. (3) Words and phrases were grouped together. Reduction of text by crossing out repetitions produced a list of higher order headings that accounted for all the data in the transcript. (4) To check for robustness of the analysis, one of the interviews was re-analyzed by an independent student of health care sciences. Furthermore two members of the research team participated in the analysis of the data. They reviewed the original transcripts to ensure that the coding frame was agreed on. (5) The abstract headings or categories were discussed and the underlying meaning was formulated into a structure of themes.

Patient quotes (in Dutch) were translated and checked for content by a native speaker.

Results

It became clear that the diagnosis of HF had brought a lot of changes in the lives of partners. Some couples had regained a new balance after some time, other couples were still struggling and in the process of adapting to their limitations in life.

Four main themes emerged from the data. Partners experienced changes in their lives as a result of the patient's disease. Partners talked about changes in daily life but also about changes in their relationship with the patient. Furthermore support from their environment and from professionals was discussed. Finally, coping was a theme that emerged from the data.

Changes in life

For many partners important changes took place since HF was diagnosed. Most changes occured during and shortly after the acute phase in which the diagnosis was made. Many partners described this period in detail. These changes mainly related to changes in daily activities as a result of new tasks for which they became responsible and former activities that decreased because of the limitations of the HF patient.

Daily life

Partners were often confronted with new tasks such as preparing the weekly medication container or calling the pharmacy for prescriptions. Partners also had to take over household tasks like taking care of the garden, taking out the garbage and doing the groceries. Sometimes these tasks were extremely intensive;

'In the beginning stayed at home for a few months, for her, there had to be somebody with her. So I took 6 to 7 weeks of from work, to care for her' (resp 12).

But most of the time these tasks were performed as a natural matter of course;

'I just did it, not that I enjoyed it very much (tending the chicken). I don't like chicken at all. It's just something you do'. (resp 2)

Joint activities

Other, probably more fundamental changes in life were changes in the daily activities of partners, either concerning personal activities or joint activities with the patient. Often the disease brought about important limitations and subsequently activities diminished:

'What we do miss is going on a holiday. We can sit here in the garden but we cannot go on a holiday. Suppose we went to Germany, to stay in a hotel. We would be in our room all day……' (resp 8).

Own life

Also the partner's own hobbies or activities became affected;

'He comes first, but it isn't easy for me either, I don't mean to complain but if you are used to go out and now you have to stay home all the time, you know all the time. My daughter lives around the corner and I go out a lot with her, with the dog, to keep my mind of things' (resp 13).

Anxiety

Almost all partners mentioned anxiety as an important experience, especially immediately after HF was diagnosed. All partners talked about the fear they felt when their spouse was outside alone, walking or visiting friends. Some partners finally learned to cope by taking appropriate measures like using a mobile telephone or simply by getting used to it. Others still lived with a lot of worries;

'I am very concerned, especially in the beginning (refering to the first, acute phase of HF), when she was at home alone and I was at work. I called her every day and when she didn't pick up the phone, then I got worried again' (resp 12).

This anxiety may also be one of the most important factors that restrict partners in their own activities;

'…….and that's about it, the cross-word and the book. And then taking the dog out for one hour, that's about it. I dare not stay away much longer. My daughter wants me to come along to go to the seaside and we will also take the dog with us, but I am afraid to go. To go out for a whole day is much too long' (resp 13).

Another source of anxiety was lying next to the patient at night. While listening to the patient's breathing pattern, partners started to worry when the patient did not seem to breathe for a while. Because of these worries, partners may experience sleep deprivation.

'At night, when he's lying in bed, and I don't hear him breath for while, it gives me the nerves. Then I start counting. And suddenly I hear him breathing again. Then I think, o dear, one morning I will wake up and then he's gone....' (resp 2).

Changes in relationship

Positive changes and solidarity

Another theme that emerged from the data was the impact that the disease had on the relationship between the partner and the HF patient. In spite of the difficult issues that partners were confronted with, some partners felt positive consequences for their relationship.

'Yes, I can safely say we have a good life together. I just did not realize I love him so much……. It is very valuable and also very special because at the time, when things were really bad, I said to myself several times 'he is still there', very special indeed...' (resp 1).

In general there was much solidarity between the partner and the patient. When the patient had to take on a diet with minimum salt, partners sometimes joined in this diet. Or when it comes to joint activities;

'We used to cycle a lot but we can't do that anymore……

Interviewer; Aren't you going alone?

'O no, I don't like that, we are going together or we don't go at all. I can go on a quick errand by myself at the local shopping centre, but once a week she comes along, in her wheel chair and that's important to her, then we do our weekly shoppings together.....' (resp 8).

Communication

But although most couples seemed to have found their way of coping with the situation, they mentioned difficult issues that put great demands on their mutual communication. One partner talked about the difficulties her husband had in regaining the balance between being active and taking rest at some point;

'When he does too much, he has to pay for it afterwards for a couple of days then he needs to recover ……He has to learn and that is difficult ……..

He can't sit still, he just can't. For two years now he has a small boat and then he goes out fishing, that's better. You just go, go fishing I said……' (resp 2).

It seems that the issue of exercising and taking rest is one that is brings up conflictive situations;

'I like to stay fit, keep exercising. Swinging, cycling, and walking. But he doesn't, he thinks it's not important. Not necessary. And I've given it a rest. He knows it is important for cardiac patients, but it's not in his nature' (resp 10).

Also well-meant concern for the patient sometimes became a source of conflict;

'He doesn't talk much. And when I ask, 'what's the matter?' Then he snaps at me and I say easy, keep calm. You really have to find a way to cope but it isn't easy, I have to admit' (resp 13).

Sexuality

Some partners mentioned their sex life had changed:

"…Perhaps less sex. Because of all the medication, it is difficult to keep it going…..… Well, I've accepted that. You have your husband in sickness and in health. So you just accept it, things happen you know" (resp 2).

or

'Well, I don't know, but…. having sex, I mean …. It is not that easy anymore but we can talk about it. It is becoming less and less (resp 5).

Coping

Passive coping

To cope with the situation respondents used different strategies. Many couples talked about their adaptation process as a process that they were going through together. Again there was a lot of mutual involvement. Partners often labeled the patient's problem as their problem as well. They even formulated their answers in terms of 'we'.

Five out of eight partners used reference to ageing as a coping strategy when giving an explanation for the disease. The following citations illustrate this finding.

'… walking for hours like we used to, that is over. But after all he is 79' (resp 5).

or like another partner said;

'Luckily I can put things into perspective… At my age, you are surrounded with women with lots of complaints, whose husbands have disorders and then you realize I can't complain. That's helpful, that helps me a lot' (resp 10).

Active coping

In order to cope with the situation sometimes the partner's own activities became more important:

'…and I managed quite well in the end. Because of my hobbies, my every day things to do and because of the freedom to do the things I want to do……. I swim twice a week, I cycle every other day into town for some shopping, I cycle with friends and I play bridge every week, I have my garden, arranging flowers, the gardenclub. Well I enjoy this very much' (resp 10).

Problems with coping

Sometimes, when patients also experienced cognitive deficiencies, couples may need professional support in finding a way to cope effectively.

'She still suffers from a mild brain damage, she will keep that. Normally you don't notice, only when she gets tired……Then I do notice, by the way she speaks I can tell she is tired. A stranger would not notice, but I do'.

'Normally she always used to be in a good mood but now when she gets tired, she becomes touchy, irritable. Then I tell her; 'go to bed' and then she does otherwise we would have a row'

This patient was seeing a psychologist;

'She was the object of these conversations, because she wasn't feeling well…….
Once I had to join to tell what was really going on……'

Interviewer; Did you like to join this conversation with the psychologist?

'Yes I liked it because finally I could tell my side of the story. He (this psychologist) only hears her side of the story, about this and that, things had to change….. And I thought, I want to tell my story too…….. Patients, they never blame themselves. It is give and take, but at times she was a shrew. Yeah really, normally she wasn't like that, she never was. Your wife is turning into another person, really more and more each time' (resp 12).

Support

Social support

It was remarkable that most partners stated that they did not talk about their situation with neighbours or friends. They said they did not feel the need for it either. Family were the most important source of support and especially children often provide practical and emotional support:

'Our daughter, she lives five minutes from here. So I always call her, 'please come over there is something wrong with your dad'. And she immediately calls the emergency number' (resp 4).

One partner indicated that she had missed recognition from relatives and friends for her specific situation:

'And than I really felt alone in it all. Because everybody would call and come over and ask, how is John? Hardly anyone asked 'how are you doing'?' (resp 10).

Support from professionals

In general partners judged the care and support from health professionals as satisfactory. However, partners did not always feel involved in the care for the HF patient. Often partners were not present during the conversation with the cardiologist or a heart failure nurse, but even when they were, they sometimes really did not feel not involved at all as one partners answered to the question 'were you involved?'

'no not really, although we were always there together, I am always present during these conversations. And I do talk……..' *(resp 8)*

Some couples went to a HF clinic and they appreciated the HF nurse highly. These nurses gave the couples the possibility to ask questions, he or she was knowledgeable about the disease and easy to contact;

'cardiologist has 10 minutes, a big threshold. I said let's go to the HF nurse, we know her and she knows everything, there we can discuss this' *(resp 10)*

Others, after suffering from heart failure for at least 18 month, still cited a need for information at times of crisis, e.g. a rehospitalization.

Discussion

The process of adaptation to HF poses complex demands on the patient but also on the partner and on the couple as a unit. In this study we conducted interviews with partners of HF patients exclusively and explored the impact of the disease on their personal lives and on their lives as a couple.

Consistent with the results of Aldred and colleagues [23] we found a profound impact of HF on the lives of HF patients and their partners. Partners indicated serious changes in their every day life and serious impact on their relationship with the HF patient. Also consistent with Aldred et al. [23] was the fact that most partners did not conceptualize their caring role as burdensome, even though in this study patients were not present during the interview. However, for some couples the losses in the previous year were more fundamental than for others, depending on the physical limitations of the patient. Some couples faced permanent loss of loved joint activities causing grief for both patient and partners.

Some of our findings need to be mentioned as they were not clearly present in the results of Aldred et al. [23] Firstly, talking about difficulties, partners often referred to the phase at the onset of the disease. Most partners described this period in detail. Furthermore, in this early period, fear and anxiety seemed clearly present. Most partners mentioned the fear of re-occurrence of the acute symptoms as they were present at the onset of the disease. These fears sometimes interfered with adequate coping strategies because they resulted in limitations of the patient's and the partner's activities, because they did not dare to leave each other for a longer time. These fears, after hospitalization and

being diagnosed as having HF, may be comparable to the anxiety experienced by partners after a cardiac event like a coronary bypass surgery or a Myocardial Infarction (MI) as described by Moore et al. [27] and Moser et al. [28] According to these investigators, anxiety is caused by increased uncertainty, grief over changes in the patient's health status, and low levels of perceived control. Anxiety of partners is an under-exposed area in clinical practise as well as in research. Family care or partner support is still not well delineated in the care for HF patients and measurement instruments on caregiver burden do not include fear and anxiety. Dracup et al. [10] stated that 'it may be that patients who experience cardiac surgery or an acute MI benefit from being the focus of the health care system, whereas partners and other family members are isolated from the support of the healthcare team and consequently experience poorer emotional recovery than patients'.

Regaining a new balance in daily schedule was an important task for HF patients as well as for their partners and mutual communication appeared to be important. Especially the balance between being active and taking rest was topic of discussion. In the beginning this seemed to be one of the most important issues in patient-partner communication. In some couples this caused stressful conversation and conflictive situations. Again, anxiety may be the underlying mechanism that caused distress and here, the quality of the marital relationship, as stressed by Coyne and colleagues, [29] may be of great importance for couples to develop adequate coping strategies together.

From the experience of one partner it was evident that mental changes, as a result of HF, can be very difficult to cope with. Since cognitive impairment in elderly patients with HF seems common, [30] it is important recognize cognitive dysfunction as a serious complication especially in the context of spousal caring.

Strength and limitations

Most, earlier qualitative studies on the impact of HF on daily life focussed specifically on patients and sometimes interviews were conducted with patients and partners together. The strength of this study lies in the fact that partners of HF patients were interviewed separately from the patients. By following this strategy we aimed to get a clearer view on the experiences of partners. However, some limitations of the study also need to be acknowledged. First the sample was small and the interviews in our study took place at least 18 months after the onset of HF. Most patients had relatively mild HF (table 1) and were in a relatively stable condition and non-hospitalized during the time of interview. Secondly, not all of those who were approached to participate were willing to do so. Some of the reasons for refusal indicate participation bias. Therefore, results of the study can not be automatically applied to partners of patients with HF in general.

Conclusion and implications for practice

The strategy of interviewing partners independently from the patient was successful and sometimes highly appreciated by these partners. Anxiety and patient-partner communication on regaining a new balance are important issues especially in the acute phases of the disease, shortly after the onset of HF or following hospitalization for HF.

It is clear that HF seriously affects the lives of patients as well as the lives of their partners. It seems important that partners become actively involved in the early rehabilitation process and recognize their importance and also their specific experiences and needs. This involvement should be more then 'being present and listen' while the patient receives education and counselling. There should be explicit focus on how patients and partners cope individually and on how patients and partners cope as a couple. From studies in other chronically ill populations it is learned that the counselling of couples can be effective in improving effective coping and reducing psychosocial distress in patients and their partners. [31;32]

References

1 Ekman I, Cleland JG, Andersson B, Swedberg K. Exploring symptoms in chronic heart failure. *Eur J Heart Fail* 2005; 7:699-703.

2 McGall D., Rahimtoola S.H. Epidemiology, etiology and natural history. Heart Failure. 1995. New York, Chapman & Hall.

3 McMurray JJV, Stewart S. The burden of heart failure. *Eur Heart J Suppl 4*, D50-D58. 2003.

4 Dracup K, Walden JA, Stevenson LW, Brecht ML. Quality of life in patients with advanced heart failure. *J Heart Lung Transplant* 1992; 11:273-9.

5 Juenger J, Schellberg D, Kraemer S, Haunsteller A, Zugck C, Herzog W, Haass M. Health related quality of life in patients with congestive heart failure: comparison with other chronic diseases and relation to functional variables. *Heart* 2002; 87:235-41.

6 Bennett SJ, Pressler ML, Hays L, Firestine LA, Huster GA. Psychosocial variables and hospitalization in persons with chronic heart failure. *Prog Cardiovasc Nurs* 1997; 12:4-11.

7 Konstam V, Salem D, Pouleur H, Kostis J, Gorkin I, Schumaker S, Mottard I, Woods P, Konstam MA, Yusuf S. Baseline quality of life as a predictor of mortality and hospitalization in 5,025 patients with congestive heart failure. SOLVD Investigations. Studies of Left Ventricular Dysfunction Investigators. *Am J Cardiol* 1996; 78:890-5.

8 Vaccarino V, Kasl SV, Abramson J, Krumholz HM. Depressive symptoms and risk of functional decline and death in patients with heart failure. *J Am Coll Cardiol* 2001; 38:199-205.

9 Luttik ML, Jaarsma T, Moser D Sanderman R, Veldhuisen van DJ. The importance and impact of social support on outcomes in patients with heart failure: an overview of the literature. *J Cardiovasc Nurs* 2005; 20:162-9.

10 Dracup K, Evangelista LS, Doering L, Tullman D, Moser DK, Hamilton M. Emotional well-being in spouses of patients with advanced heart failure. *Heart Lung* 2004; 33:354-61.

11 Evangelista LS, Dracup K, Doering L, Westlake C, Fonarow GC, Hamilton M. Emotional well-being of heart failure patients and their caregivers. *J Card Fail* 2002; 8:300-5.

12 Karmilovich SE. Burden and Stress Associated with Spousal Caregiving for Individuals with Heart Failure. *Prog Cardiovasc Nurs* 1994; 9, 33-38.

13 Luttik ML, Jaarsma T, Veeger NJ, van Veldhuisen DJ. For better and for worse: Quality of life impaired in HF patients as well as in their partners. *Eur J Cardiovasc Nurs* 2005; 4:11-4.

14 Rohrbaugh MJ, Cranford JA, Shoham V, Nicklas JM, Somega JC, Coyne JC. Couples coping with congestive heart failure: role and gender differences in psychological distress. *J Fam Psychol* 2002; 16:3-13.

15 Pinquart M, Sorensen S. Differences between caregivers and noncaregivers in psychological health and physical health: a meta-analysis. *Psychol Aging* 2003; 18:250-67.

16 Schulz R, Beach SR. Caregiving as a risk factor for mortality: the Caregiver Health Effects Study. *JAMA* 1999; 282:2215-9.

17 Vitaliano PP, Zhang J, Scanlan JM. Is caregiving hazardous to one's physical health? A meta-analysis. *Psychol Bull* 2003; 129:946-72.

18 Coyne JC, Smith DA. Couples coping with a myocardial infarction: a contextual perspective on wives' distress. *J Pers Soc Psychol* 1991; 61:404-12.

19 Martensson J, Dracup K, Canary C, Fridlund B. Living with heart failure: depression and quality of life in patients and spouses. *J Heart Lung Transplant* 2003; 22:460-7.
20 Scott LD. Caregiving and care receiving among a technologically dependent heart failure population. *ANS Adv Nurs Sci* 2000; 23:82-97.
21 Brecht ML, Dracup K, Moser DK, Riegel B. The relationship of marital quality and psychosocial adjustment to heart disease. *J Cardiovasc Nurs* 1994; 9:74-85.
22 Martensson J, Dracup K, Fridlund B. Decisive situations influencing spouses' support of patients with heart failure: a critical incident technique analysis. *Heart Lung* 2001; 30:341-50.
23 Aldred H, Gott M, Gariballa S. Advanced heart failure: impact on older patients and informal carers. *J Adv Nurs* 2005; 49:116-24.
24 Jaarsma T, van der Wal MH, Hogenhuis J, Lesman J, Luttik ML, Keeger NJGM, Veldhuisen van DJ. Design and methodology of the COACH study: a multicenter randomised Coordinating study evaluating Outcomes of Advising and Counselling in Heart failure. *Eur J Heart Fail* 2004; 6:227-33.
25 Burnard P. Teaching the analysis of textual data: an experiential approach. *Nurse Educ Today* 1996; 16:278-81.
26 Graneheim UH, Lundman B. Qualitative content analysis in nursing research: concepts, procedures and measures to achieve trustworthiness. *Nurse Educ Today* 2004; 24:105-12.
27 Moore SM. Psychologic distress of patients and their spouses after coronary artery bypass surgery. *AACN Clin Issues Crit Care Nurs* 1994; 5:59-65.
28 Moser DK, Dracup K. Role of spousal anxiety and depression in patients' psychosocial recovery after a cardiac event. *Psychosom* Med 2004; 66:527-32.
29 Coyne JC, Rohrbaugh MJ, Shoham V, Sonnega JS, Nicklas JM, Cranford JA. Prognostic importance of marital quality for survival of congestive heart failure. *Am J Cardiol* 2001; 88:526-9.
30 Trojano L, Antonelli Inc, Acanfora D, Picone C, Mecocci P, Rengo F. Cognitive impairment: a key feature of congestive heart failure in the elderly. *J Neurol* 2003; 250:1456-63.
31 Kuijer RG, Buunk BP, De Jong GM, Ybema JF, Sanderman R. Effects of a brief intervention program for patients with cancer and their partners on feelings of inequity, relationship quality and psychological distress. *Psychooncology* 2004; 13:321-34.
32 van den Heuvel ET, de Witte LP, Nooyen-Haazen I, Sanderman R, Meyboom-de Jong B. Short-term effects of a group support program and an individual support program for caregivers of stroke patients. *Patient Educ Couns* 2000; 40:109-20.

For Better and for Worse:
quality of life impaired in HF patients as well as in their partners

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Abstract

Background

Quality of Life (QoL) is known to be impaired in patients with Heart Failure (HF). The involvement of a key person, most often the spouse, enables the HF patient to manage the medical regimen and therefore to sustain QoL. Yet little is known on the impact of caring for a HF patiënt on the QOL of the caregiving partner. This study aims to explore the QoL of partners of HF patients compared to the QoL of the patients.

Methods

The study population consisted of 38 couples of hospitalized HF patients and their partners. The Cantril Ladder of Life was used to rate QoL during hospitalization, with regard to the month before hospitalization and as projected three years in the future. Demographic and clinical variables were collected by patient interview and chart review.

Results

On a scale from 0-10, QoL scores of partners varied from 5.9 to 6.4. At some point the QOL score of partners was even lower than the QoL scores of HF patients. In the month before hospital admission the QoL of partners was significantly higher in comparison to the QoL of HF patients (6.1 vs. 4.9 respectively). However, this reversed during hospital admission, with QoL scores of partners being significantly lower compared to QoL scores of HF patients (5.9 vs. 6.8 respectively), even after correcting for age and gender.

Conclusion

In our study the QoL of partners of HF patients was low. Whether this is explicitly due to having to live with a HF patient. Further research on what partners actually do and the relationship between being a caregiver and QoL is necessary in order to support these partners in giving optimal care and support.

Introduction

Heart Failure (HF) is a complex illness with serious consequences for patients and their families. Recent evidence suggests that morbidity and mortality rates are improving [1] however, HF remains at least as malignant as cancer in both men and women. [2] Despite advances in medical treatment, the prognosis of patients with HF remains poor. Because of this, Quality of Life (QoL) has become an important complementary end-point to morbidity and mortality. HF is now primarily managed by symptom control and the treatment consists of a complex regimen of medication, dietary prescriptions, fluid restriction, exercise and symptom monitoring. Following this regimen seriously affects the lives of patients and their families, especially their spouses or partners.

Social support is an important factor in managing health and disease. [3] It is also clear that support resources are essential for survival and adjustment to cardiovascular disease. [4] Cardiac patients who are living alone, [5] socially isolated [6] or without emotional support [7,8] are at risk for recurrent cardiac events and decreased physical and mental well-being.

On the other hand it is known that psychological and physical health of spouses of chronically ill elderly people is negatively affected, [9] especially in female spouses. Disease specific characteristics such as cognitive functioning and prognosis play an important role in the amount of burden experienced. Several studies on the impact of Myocardial Infarction (MI) on the family describe severe consequences. High levels of physical and emotional distress in partners of MI patients were found. [10,11]

Only few studies describe the specific situation of partners of HF patients. Karmilovich [12] was the first who found that providing care to HF patients can be burdensome and stressful. The most significant burden seemed to be related to the emotional component in the relationship between partners that can be altered when dealing with HF. Both Rohrbaugh [13] and Martensson [14] studied HF patients and their spouses as a couple on psychological distress, depression and QoL. Rohrbaugh found high levels of psychological distress in HF patients as well as in their spouses. Martensson described different levels of depression and QoL in HF patients and their spouses with patients experiencing more depressive symptoms and worse physical QoL. Mental QoL did not differ between patients and partners which, according to the authors, may indicate that the disease affects the psychological well-being of married couples equally. Well-being of the partner was also found to be an important predictor of the patiënt's well-being. [15] Further exploration of the impact of HF on patients as well as on their partners, is necessary in order to develop optimal patient care.

The aim of this study was to explore the QoL of partners of HF patients and furthermore, to compare these outcomes with the QoL of HF patients.

Methods

Patients and partners

All patients in the present study participated in the study of Jaarsma et al [16] on the effect of education and support on QoL in patients with HF. The 179 HF patients in this study were admitted with symptoms of HF to a University Hospital in the Netherlands from March 1994 to March 1997. The patients had symptoms of HF for at least 3 months, had been classified by the attending physician as New York Heart Association Class (NYHA) III or IV, were over 50 years of age and were literate in Dutch.

The study was performed conform the principles outlined in the declaration of Helsinki and was approved by the hospital ethics committee.

Measures

QoL was measured during admission by the Cantril Ladder of Life. [17] This instrument has been used in various cardiovascular studies and is considered to be a valid measure of 'global well-being'. [18,19] Although this measure of global well being does not cover QoL as a multi dimensional concept, it is related to important aspects of QoL such as psychosocial adjustment and functional capabilities. [20]

Patients and partners were asked to rate their sense of well-being on a scale 0-10 (10 reflecting the best and 0 reflecting the worst possible life). They were asked to do so during hospital admission (after being treated and stabilized), with regard to the time of interview, with regard to the month before hospital admission and with regard to their expectations of well-being for 3 years in the future.

Demographic variables and clinical data of patients were collected by chart review, partners completed a short questionnaire.

Analysis

All data were entered into an SPSS database. Data from the Cantril Ladder of Life were considered continuous. To answer the research question we analysed the 38 couples of HF patients and their partners who both completed the Cantril Ladder, in order to compare QoL between patients and partners using an unpaired Student t-test. Baseline descriptive statistics were mean and standard deviation for continuous variables, and frequencies with percentages for the categorical variables. Multivariate analysis was used to correct the results for potential confounders.

Results

Study population

All partners of married patients (N=96) who were able to read and write in Dutch, were asked to complete a short questionnaire. In total 40 partners completed this

questionnaire, two partners were excluded because of missing data of the patient. Patients whose partners completed the questionnaire and those patients whose partners did not complete the questionnaire, did not differ on age, gender and NYHA class.

The study population consisted of 38 HF patients and their spouses who both completed the QoL ladder. This population consisted of 31 male patients and 7 female patients and 32 female spouses and 6 male spouses. Demographic and clinical data are presented in table 1.

Table 1. Demographic and clinical data HF patients and partners (n=38)

	Patients	Partners
Age (mean, sd.)	68 (±8)	64 (±9)
Male sex (N, %)	31 (82)	6 (16)
LVEF (mean, sd.)	29% (±11)	-
NYHA (%)		-
III	24%	
III-IV	26%	
IV	50%	

Self-reported QoL of patients and partners

The mean self-reported QoL scores of the partners were more or less stable in time. The scores varied from 6.1 in the month before hospital admission of the patient, 5.9 during hospital admission and 6.4 for future expectations (table 2). The QoL scores of HF patients were more variable over time with a low QoL score of 4.9 in the month before hospital admission, a considerably higher score of 6.8 during hospital admission and 6.7 for future expectations.

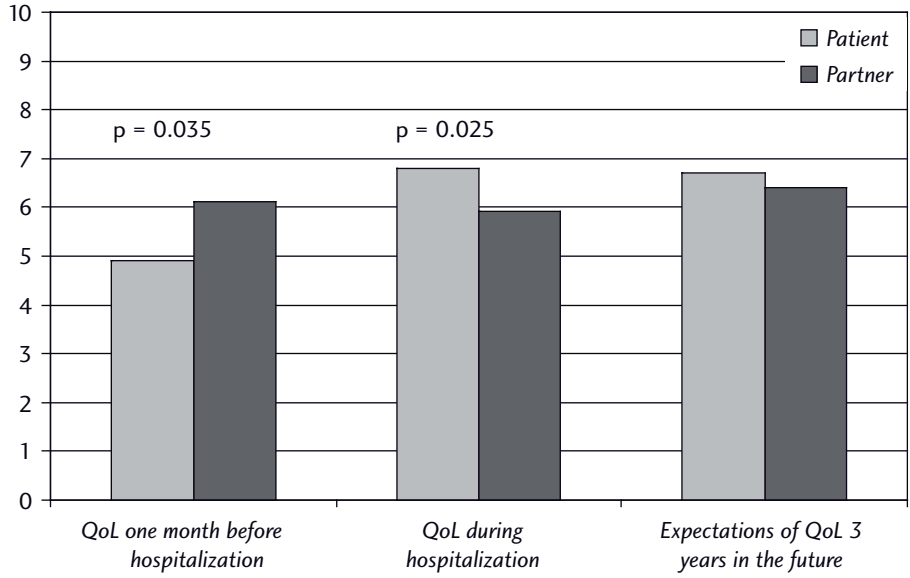
Self-reported QoL of partners compared to the self-reported QoL of HF patients

Univariately the QoL scores of HF patients and their partners differed significantly (table 2, figure 1). Considering the differences in age and gender between the two groups, a multivariate analysis was performed in order to correct for these potential confounders. In the month before hospital admission, HF patients rated their QoL significantly lower than partners do (4.9 vs. 6.1, p=0.035). Multivariate analysis showed that this difference was independent of age and gender. At the time of hospital admission, after being stabilized the QoL of HF patients increased above the QoL as reported by the partners. Partners had a significantly lower QoL score than HF patients (5.9 vs. 6.8, p=0.025). After correcting for age and gender, differences in QoL scores between partners and patients remained statistically significant. The scores of patients and partners on expectations about the QoL 3 years in the future seemed rather correspondent and did not differ significantly (6.7 vs. 6.4, p=0.60).

Table 2. Mean (sd.) QoL scores of HF patients and their partners (n=38)

	HF patients	Partners	p-value
QOL now	6.8 (±1.7)	5.9 (±1.6)	0.02
QOL past	4.9 (±2.6)	6.1 (±2.3)	0.03
QOL future	6.7 (±2.0)	6.4 (±2.1)	0.60

Figure 1. Differences in mean QoL scores of HF patients and their partners



Discussion

This article describes an explorative study on the Quality of Life (QoL) of HF patients and their partners. We found that QoL of HF patients is rather low (between 4.9 and 6.8). The average QoL score of 6.8 of the HF patients during hospital admission in our study was lower compared to the QOL scores of patients in cardiac rehabilitation (8.0) and patients after cardiac surgery (7.5).[19,21] This may well be explained by the better life expectancy of these two groups.

For partners of HF patients we also found low QoL scores (between 5.9 and 6.4). If we consider partners to be members of a healthy, elderly population we can compare our findings with the study of Ormel et al.[22] They reported, in a population of 573 healthy, elderly people, a mean score of 7.9 on the Cantril Ladder. Thus, comparing our findings to these results, it must be concluded that the QoL scores of partners in our population are considerably lower. These findings are congruent with the findings of Kriegsman[9] that spouses of chronically ill

patients in general feel burdened, especially when patients have a bad prognosis.

Looking at the course of the QoL scores of patients and partners it is apparent that the QoL scores of partners are more or less stable in time, whereas the scores of HF patient fluctuate in time. It seems striking to find that at some point, during hospital admission, partners of HF patients have a lower QoL score than HF patients, even after correcting for age and gender as potential confounders. This was in contrast to Martensson, [14] who found a worse or equal QoL in patients with HF compared to partners. These results may be due to varying QoL scores of HF patients, probably as a consequence of a worse clinical status before hospital admission which improves as a result of the medical treatment during hospital admission. The QoL score of HF patients during hospital admission may therefore be relatively high due to a feeling of relief after the physical crisis is being treated.

Still the low QoL scores of spouses remains disturbing and they might indicate that caring for a HF patient has an impact on the well-being of these caring spouses. Whether these results are explicitly due to the fact of having to live with a HF patient remains to be answered since some limitations of our study should be considered when interpreting the findings.

The study was limited by a small sample size and by the restricted information that was available about the partners of HF patients. Some potentially confounding variables (e.g. health status of the partners) could not be included in the analysis. The use of the Cantril Ladder of Life as an indicator of QoL can be argued. It certainly does not cover the whole multidimensional meaning the concept of QoL.

Furthermore, we did not investigate whether it is the caregiving role that affects their well-being or the influence of other factors. Further research, in which the concept of QoL in partners is assessed more in depth, is necessary to achieve more understanding of the relationship between care giving and QoL.

Conclusion

In conclusion this study indicates that the QoL of partners seems to be affected by caring for a HF patient and it is apparent that our knowledge about this group is insufficient. In our attempts to improve outcome in HF patients we can not ignore the possible burden of the caregiving partner. All the more because literature suggests that having support of a partner is essential for outcomes in HF patients. We need to investigate this group on their own characteristics, their well-being in relation to their role as caregiver and their needs for advice and counselling in order to give optimal care and support.

Acknowledgements

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References

1 MacIntyre K, Capewell S, Stewart S, Chalmers JW, Boyd J, Finlayson A, Redpath A, Pell JP, Mc Murray JJ. Evidence of improving prognosis in heart failure: trends in case fatality in 66 547 patients hospitalized between 1986 and 1995. *Circulation* 2000; 102:1126-31.

2 Stewart S, MacIntyre K, Hole DJ, Capewell S, McMurray JJ. More 'malignant' than cancer? Five-year survival following a first admission for heart failure. *Eur J Heart Fail* 2001; 3:315-22.

3 Berkman LF. The role of social relations in health promotion. Psychosom Med 1995; 57:245-54.

4 Reifman A. Social relationships, recovery from illness, and survival: A literature review. *Annals of behavioral medicine* 1995; 17:124-31.

5 Case RB, Moss AJ, Case N, McDermott M, Eberly S. Living alone after myocardial infarction. Impact on prognosis. *JAMA* 1992; 267:515-19.

6 Ruberman W, Weinblatt E, Goldberg JD, Chaudhary BS. Psychosocial influences on mortality after myocardial infarction. *N Engl J Med* 1984; 311:552-59.

7 Krumholz HM, Butler J, Miller J, Vaccarino V, Williams CS, Mendes de Leon CF, Seeman TE, Kasl SV, Berkman LF. Prognostic importance of emotional support for elderly patients hospitalized with heart failure. *Circulation* 1998; 97:958-64.

8 Williams RB, Barefoot JC, Califf RM, Haney TL, Saunders WB, Pryor DB, Hlatky MA, Siegler IC, Mark DB. Prognostic importance of social and economic resources among medically treated patients with angiographically documented coronary artery disease. *JAMA* 1992; 267:520-24.

9 Kriegsman D.M.W., Penninx B.M.J.H., van Eijk J.Th.M. Chronic Disease in the Elderly and Its Impact on the Family: A Review of the Literature. *Family Systems Medicine* 1994; 12:249-67.

10 Moore SM. Psychologic distress of patients and their spouses after coronary artery bypass surgery. *AACN Clin Issues Crit Care Nurs* 1994; 5:59-65.

11 Moser DK, Dracup K. Role of spousal anxiety and depression in patients' psychosocial recovery after a cardiac event. *Psychosom Med* 2004; 66:527-32.

12 Karmilovich SE. Burden and Stress Associated with Spousal Caregiving for Individuals with Heart Failure. *Prog Cardiovasc Nurs* 1994; 9:33-8.

13 Rohrbaugh MJ, Cranford JA, Shoham V, Nicklas JM, Sonnega JS, Coyne JC. Couples coping with congestive heart failure: role and gender differences in psychological distress. *J Fam Psychol* 2002; 16:3-13.

14 Martensson J, Dracup K, Canary C, Fridlund B. Living with heart failure: depression and quality of life in patients and spouses. *J Heart Lung Transplant* 2003; 22:460-67.

15 Evangelista LS, Dracup K, Doering L, Westlake C, Fonarow GC, Hamilton M. Emotional well-being of heart failure patients and their caregivers. *J Card Fail* 2002; 8:300-5.

16 Jaarsma T, Halfens R, Huijer Abu-Saad H, Dracup K, Gorgels T, van Ree J, Stappers J. Effects of education and support on self-care and resource utilization in patients with heart failure. *Eur Heart J* 1999; 20:673-82.

17 Cantril H. The pattern of human concerns. New Brunswick: Rutgers University, 1965.

18 Jaarsma T, Kastermans MC. Recovery and quality of life one year after coronary artery bypass grafting. *Scand J Caring Sci* 1997; 11:67-72.

19 Senten CMS. The well-being of patients having CAB surgery: a test of Orem's self-care nursing theory. Maastricht: University of Maastricht, 1991.
20 Jaarsma T, Halfens R, Abu-Saad HH, Dracup K, Stappers J, van Ree J. Quality of life in older patients with systolic and diastolic heart failure. *Eur J Heart Fail* 1999; 1:151-60.
21 Packa DR, Branyon ME, Kinney MR, Khan SH, Kelley R, Miers LJ. Quality of life of elderly patients enrolled in cardiac rehabilitation. *J Cardiovasc Nurs* 1989; 3:33-42.
22 Ormel J, Kempen GI, Deeg DJ, Brilman EI, van Sonderen E, Relyveld J. Functioning, well-being, and health perception in late middle-aged and older people: comparing the effects of depressive symptoms and chronic medical conditions. *J Am Geriatr Soc* 1998; 46:39-48.

The objective burden in partners of heart failure patients:
development and initial validation of the Dutch Objective Burden Inventory (DOBI)

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Submitted

Abstract

Background

Measures on objective caregiver burden in partners of Heart Failure (HF) patients are hardly available and never include HF specific aspects. The main objective of our study was to develop an inventory that assesses the objective caregiver burden of partners of HF patients, including the full range of potential care giving demands.

Methods

To develop the inventory, 6 domains of caregiving demands were identified. Items for the domains were generated from literature, existing scales and expert opinion. The original 50-items self-report inventory was administered to 321 partners of HF patients. Demographic data of HF partners were collected by questionnaire. Clinical data of the HF patients were collected by chart review.

Results

Component analysis led to the exclusion of 12 original items and to a meaningful four-component solution with a total explained variance of 43%. The components reflected four different domains of care giving tasks; personal care, emotional, motivational and practical/treatment related support. The components demonstrated good internal consistency and initial validity was supported by a pattern of meaningful associations with external variables.

Conclusion

The Objective Burden Inventory is a promising inventory to assess objective care giving tasks (and task related burden) performed by HF partners. It provides information on the caregiver situation that may help to develop effective interventions.

Background

Within our current health care system the care for patients with Heart Failure (HF) for the most part takes place within the patient's home and with the help of partners and families. Research has made it clear that the support of a partner is essential in managing the disease. [1] There is also evidence that the support of a partner has positive impact on outcome measures in cardiac patients in general [2] and in patients with HF. [3-5] Nevertheless, very little attention has been given to role and position of these partners, let alone to the consequences of the disease on their lives. [6] Only a few studies are known in this research area and these studies indicate that partners experience higher levels of psychosocial distress and lower well-being compared to the general population [7-9] and even may be at risk for physical and mental morbidity and eventually for earlier death. [10] Caregiver burden as an outcome measure has been studied only twice in partners of HF patients. [11,12]

In analysing the caregiver situation a distinction is made between objective and subjective burden. [13,14] This distinction aims to seperate events and activities from feelings and emotions. Objective burden refers to the concrete activities and tasks that caregivers perform resulting from the care giving process. Subjective burden refers to the caregiver's appraisal of the care giving situation and the extent to which the caregiver perceives the situation as burdensome. [13] Both aspects of burden are relevant and it is important to distinguish since objective and subjective burden seem to be only moderately correlated and therefore the same levels of objective burden may result in different levels of subjective burden. [13] Interventions to relieve objective burden may need to be different from interventions that relieve subjective burden. Understanding these relationships is important for the development of effective supportive interventions in the future.

Subjective feelings of burden can be measured by a variety of instruments that are designed to assess this concept in caregivers of chronically ill such as the Caregiver Strain Index [15] or the Caregiver Reaction Assessment Scale (CRA). [16]

Instruments that focus on the objective caregiver burden are scarce. Despite the relevance of both objective and subjective components of burden both aspects are not well separated and the measurement of caregiver burden often contains both. Generally objective caregiver burden is measured by a random set of questions that reflect a certain set of tasks. There is no consistency in the kind of tasks that are assessed and emotional support is seldom defined as a specific type of care giving task. [17]

HF is a life-threatening condition with serious consequences in daily life. The course of the disease is characterized by debilitating physical symptoms, frequent hospitalizations and poor prognosis. [18] Treatment consists of a complex regimen of multiple medications, dietary sodium restriction, increase or maintenance of activity levels, symptom monitoring, and for some patients, fluid restriction.

Depending on the physical condition of the patient, partners have to assist in personal care and in household activities. However, patients with HF probably need predominantly emotional and motivational support in complying with the complex medical regimen and prescribed lifestyle changes. [19]

The aim of the study was to develop a comprehensive inventory to assess the full range (kind, number and frequency) of performed care giving tasks of partners of HF patients, including emotional and motivational care giving tasks. We were also interested in the amount of perceived burden related to specific care giving tasks. This article describes the development and first order testing of a new measure to assess the objective burden in partners of HF patients.

Methods

The methodological steps employed in this study were [1] to develop the Objective Burden Inventory and [2] to explore its psychometric properties.

1 Development of the inventory

Based on the presumption that the full range of tasks needs to be assessed, the inventory should contain prespecified domains of caregiving tasks. The following 6 domains were identified; assistance in physical care and transportation, feeling responsible and being available, assistance in household activities, assistance in financial activities, assistance in disease related activities and emotional or motivational support in following the treatment regimen. To fill these domains items were generated from literature and existing scales. [20-22] Treatment related tasks were derived from the European Guidelines on Heart Failure Management, [23] such as supporting the patient in following the prescribed diet or in trying to quit smoking.

For each specific task two questions referring to the previous 3 months, were formulated (1) if (and how often) the partner performed this tasks and (2) if yes how burdensome this was for them. A 3 point Likert-type response format for the assessment of performed tasks was developed, ranging from never (1), to sometimes (2), to always (3). Subsequently a 3 point Likert scale was developed to score task related burden from no burden (1), to somewhat burden (2), to severe burden (3) The final selection of items was presented to a team of specialized HF nurses and three partners of HF patients, known at the HF clinic. HF nurses and partners were asked to judge the item selection on its content (are there items missing?, are there items irrelevant?) and its feasibility and clarity of questioning. In answer to their reports no items were removed, some were rephrased (box 1).

2 Subjects

Data were gathered from partners of HF patients that participated in the Dutch NHF-COACH trial on the effects of advising and counselling in HF patients. [24]

Box 1

Eating, drinking, personal care and moving
In the previous 3 months, did you support your partner:
1. in eating and drinking
2. in preparing meals
3. in planning and organizing meals
4. in washing and bathing
5. in dressing and un-dressing
6. in going to the toilet
7. in assisting with appearance
8. in walking in and around the house
9. in coming in and out of bed or chair
10. in walking stairs
11. with transportation to health care providers
12. with transportation to family and friends
13. in using the telephone
14. by helping with comfortable position in bed
Household activities
Are you the one that:
15. performs the light household activities (dusting, doing the dishes)
16. performs the heavy household activities (vacuuming, washing floors)
17. does the shopping
Services
Are you the one that:
18. does the finances
19. fills in forms of reimbursement
20. arranges care when necessary
21. arranges physical aids when necessary
Responsibility and availability
Which of the following statements fits to your personal situation?
22. I have to be available for 24 hours to take care of my partner
23. my partner also needs my help frequently at night
24. when I am away, I have to arrange someone else to stay with my partner

Treatment related
In the previous 3 months did you support your partner;
25. in preparing medication
26. in taking the medication
27. in achieving prescriptions for medication
28. in achieving medication
29. in evaluating the need for (extra) diuretics
30. in monitoring symptoms of deterioration
31. in contacting a professional when things get worse
32. in contacting a professional in case of problems or questions
33. in following the fluid prescriptions
34. in following the diet prescriptions
35. in regular weighing
36. in following the prescriptions of activity and exercise
37. in taking care of rest in daily life
Emotional
In the previous 3 months, did you support your partner;
38. by providing comfort
39. by talking to reduce anxiety
40. by talking to reduce depressive feelings
41. by talking about worries and problems
42. by showing understanding
43. by keeping company
44. by motivating to stick to the diet prescriptions
45. by motivating to quit or reduce smoking
46. by motivating to activities and exercise
47. by motivating to take medications (in time)
48. by motivating to stick to the fluid prescriptions
49. by motivating to start working again
50. by attending conversations with physicians and other health care professionals

All patients were included during a hospital admission for HF (NYHA II-IV). Patients were at least 18 years of age, with evidence of structural underlying heart disease. All partners (if available) of the participating patients were approached one year after the HF patient was discharged. Partners received the study questionnaire by mail at home and were asked to fill in the questionnaire independently from the patient. Independent datacollectors visited patients and partners at home to collect the questionnaires. There were no specific in- or exclusion criteria except for partners to be able to read and understand the Dutch language and to be mentally able to complete a questionnaire.

Demographic and clinical data of patients were collected by chart review and patient interview at baseline, during hospital admission.

3 Statistical analysis

First the feasibility of the inventory was assessed by exploring the number of missing values per respondent and per item.

a After this assessment we conducted a Principle Component Analysis (PCA) in order to explore the structure or underlying dimensions within the data set and to reduce the number of items, if possible. The criteria used for a component's extraction were the scree plot, an Eigenvalue above 1.00 and each component to account for at least 5% of the variance among the items. To improve the interpretation of the component extraction a varimax rotation was applied. Selection of items was based on the following criteria; (a) an item loading exceeding 0.40, (b) second highest loading was at least 0.20 lower.
   For task related burden a Simultaneous Component Analyses (SCA) [26] was used to check whether the component structure found within the performed care giving tasks also fits the data set on task related burden. This fit depends on the difference in percentages of explained variance between the forced or assigned structure and an exploratory structure over the same data set, as derived by the SCA.

b Reliability was explored by using the Cronbach's alpha as a measure of internal consistency. In general, homogeneity is considered to be sufficient if alpha ranges between 0.70 and 0.90. [25]

c For each extracted component scores were computed by adding the item values in each component and then dividing them by the number of items in that component.

d Some first order tests on construct validity of the components can be done with the help of external variables or criteria which are expected to be related. For this purpose the four components were correlated with gender, health status of HF patients and subjective feelings of burden. Based on literature we expected:
   1. Gender to be positively related to the number of performed care giving tasks and the amount of task related burden, with women performing more care tasks and perceiving more task related burden; [11, 27]

2. Care giving tasks regarding personal care to be correlated with the severity of HF and the physical health status of the patient; a worse health status is expected to result in more caregiving tasks regarding personal care; [28]
3. Care giving tasks regarding emotional support to be related with mental health status and depressive symptoms of HF patients; patients with a low mental health status or symptoms of depression will be in need for more emotional en motivational support; [28]
4. Subjective feelings of caregiver burden to be associated with performed care giving tasks and with task related burden. The performance of caregiving tasks and task related burden are expected to result in subjective feelings of burden.[13,14]

Table 2 provides an overview of the instruments that were used to measure the different variables. Physical health of the HF patient was assessed by the subscale physical functioning of the RAND 36. [29] Severity of HF was defined by the NYHA classification (New York Heart Association). Mental health of the HF patient was assessed by the subscale mental functioning of the RAND 36 and by the Centre of Epidemiologic Studies Depression Scale (CES-D). [30] Feelings of subjective caregiver burden were measured by the Caregiver Reaction Assessment Scale [16] at 12 months after patient discharge.

Table 2. Variables and measurements

Variables	Measurement
Demographics Age, gender and educational level	Chart review and patient interview
Physical health status HF patient	NYHA classification* RAND 36 Physical functioning
Mental health status HF patient	RAND 36 Mental functioning Center of Epidemiologic Studies Depression Scale (CES-D)
Subjective caregiver burden	Caregiver Reaction Assessment scale (CRA)

**NYHA class = New York Heart Association, functional class*

I= no limitation of physical activity, II= slight limitation of physical activity,

III= marked limitation of physical activity, IV= unable to carry out physical activity without discomfort

Results

Study population

Our study population consisted of 321 partners of HF patients. Partners were predominantly female (75%) and had a mean age of 67 years. Patients were slightly older (70 yrs) and predominantly male. Fifty-seven percent of all HF patients had one or more comorbidities (table 3).

Table 3. Study population (n=321)

		Mean or % (sd)
Partner characteristics		
Age	yrs	67 ±12
Gender	female	75%
Educational level*	low	54%
Patient characteristics		
Age	yrs	70 ±12
Gender	male	75%
Physical functioning RAND 36		39 ±28
NYHA class	II	53%
	III-IV	47%
LVEF (%)		32 ±14
Number of comorbidities	None	43%
	One	33%
	2-5 comorbidities	24%

** educational level low = no education/primary school/lower vocational school*

Feasibility

The instrument was filled out without main difficulties. In total 250 (78%) respondents had no missing values, 57 (18%) respondents had only one or two items missing. Missing values for all separate items on care giving tasks was below 5%. For task related burden fifty-one percent of the respondent had no missing values, 8% of the respondents had more than 12 (25%) items missing.

Constructing components

Based on the scree plot, four components were extracted. These four components explained 43% of the total variance (table 4). All components had an Eigenvalue above 1.00. The first component explained most variance (22%) and consisted of tasks regarding **personal care** (eg. assisting in washing, in eating and drinking). The second component, explained 7.5% of the total variance and contained tasks related to **motivating** the HF patient in following the prescribed treatment regimen (eg. motivating to follow diet prescriptions). The third component referred to **emotional support** and accounted for an additional 7%. The final component contained **practical** tasks like household activities and **treatment related** tasks like achieving medication. This component explained 5.6 % of the total variance.

After running several analyses 15 items did not meet the selection criteria, they were either loading below 0.40 or were loading high on more than one component. Of these 12 items were removed from the inventory (table 5). There were three items (15, 45 and 50 see table 4) that remained in the inventory because their content seemed very relevant.

Table 4. Rotated Component Matrix with Percentage of Explained Variance and Crohnbach's Alpha

		Component			
In the previous 3 months did you support the patient in or by		**1[1]**	**2[2]**	**3[3]**	**4[4]**
Eating and drinking	1a	.67			
Washing and bathing	4a	.60			
Dressing	5a	.69			
Toileting	6a	.67			
Assisting with appearance	7a	.49			
Mobility at home	8a	.61			
Helping in and out of bed	9a	.80			
Walking stairs	10a	.63			
Helping with comfortable position in bed1	14a	.72			
Household activities light	15a		.31		.37
Household activities heavy	16a				.44
Shopping	17a				.51
Doing the finances	18a				.70
Filling in forms of reimbursement	19a				.67
Arranging care when necessary	20a				.66
Arranging physical aids	21a				.71
Availability for 24 hours	22a	.44			
Caring at night	23a	.50			
Achieving prescription for medication	27a				.54
Achieving medication	28a				.54
Contacting a professional	32a				.42
Following fluid prescriptions	33a		.64		
Following diet prescriptions	34a		.57		
Regular weighing	35a		.55		
Following exercise prescriptions	36a		.49		
Providing comfort	38a			,.74	
Talking to reduce anxiety	39a			.76	
Talking to reduce depressive feelings	40a			.78	
Talking to reduce worries	41a			.76	
Showing understanding	42a			.64	
Keeping company	43a			.57	
Motivating to follow diet	44a		.61		
Motivating to quit smoking	45a		.33		
Motivating to be active	46a		.53		
Motivating to take medications	47a		.69		
Motivating to follow fluid prescriptions	48a		.73		
Motivating to start working again	49a		.43		
Participating in conversations with professionals	50a			.36	.35
Percent of variance explained		**22.75**	**7.48**	**7.12**	**5.62**
Crohnbach's Alpha		**0.83**	**0.81**	**0.84**	**0.81**

[1] = personal care, [2] = motivational support, [3] = emotional support, [4] =practical support

Table 5 Items that were removed from the initial 50-item selection

In the previous 3 months, did you support your partner:
1. in preparing meals
2. in planning and organizing meals
3. with transportation to health care providers
4. with transportation to family and friends
5. in using the telephone
6. in preparing medication
7. in taking the medication
8. in evaluating the need for (extra) diuretics
9. in monitoring symptoms of deterioration
10. in contacting a professional when things get worse
11. in taking care of rest in daily life
12. when I am away, I have to arrange someone else to stay with my partner

The 38 items that were retained were again analysed and did fit in the four factor model with the labels as indicated earlier.

A Simultaneous Component Analyses (SCA) was used to check whether the component structure as found within the performed care giving tasks also fits the task related burden. PCA on task related burden (38 items) over four components explained 43.78%, whereas a SCA explained 41.72%. This difference of 2.06% is considered acceptable meaning that the same components as found in the performance of care giving tasks can be applied to task related burden.

The total component scores for performed care giving tasks and task related burden are presented in table 6.

Table 6. Mean scores (sd) for performed care giving tasks and task related burden

Performed care giving tasks*	**Mean (sd)**
Personal care	1.16 (0.3)
Motivational support	1.43 (0.4)
Emotional support	1.82 (0.5)
Practical support	1.97 (0.5)
Task related burden*	**Mean (sd)**
Burden related to personal care tasks	1.04 (0.1)
Burden related to motivational support	1.07 (0.2)
Burden related to emotional support	1.13 (0.3)
Burden related to practical support	1.13 (0.2)

** Range 1-3*

Reliability

The internal consistency of the components was calculated using the Crohnbach's alpha. As shown in table 4, the components displayed alpha scores from 0.81 to 0.84. Reliability of the task-related burden components varied from 0.74 to 0.89.

Inter correlation

Rather independent subscales of performed care giving tasks are measured by the different components as reflected by the component correlation matrix which showed fairly low correlation (ranging from 0.18 to 0.29) between the separate components.

Correlation coefficients between the amount of performed care giving tasks and the task related burden in a certain component indicate that there is a relationship, correlation coefficients varied from 0.23 to 0.52.

Construct validity

The correlations with external variables present a preliminary test of the construct validity of the components of caregiving tasks. We found weak correlations between gender and the components of caregiving tasks. Female partners tended to perform more motivational care tasks (r=-0.18) whereas men tended to perform more personal care tasks (r=0.13). Task related burden was more present in women, (r ranging from -0.08 to -0.19). As expected, it was found that severity of HF as indicated by the NYHA classification and by the RAND 36 physical functioning is positively associated with the number of performed care giving tasks regarding personal care (r=0.22 and r=-0.26 respectively). Furthermore, mental health status and depressive symptoms of HF patients correlated fairly high and in the expected direction (r=-0.20 and r=0.17 respectively). Finally, the components of caregiving tasks were moderately correlated with subjective feelings of burden, especially with the CRA subscale 'disruption of daily schedule' (r ranging from 0.32 to 0.50). Task related burden appeared correlated with the CRA subscale 'disruption of daily schedule' (r ranging from 0.29 to 0.41) and 'loss of physical strength' (r ranging from 0.26 to 0.42).

Discussion

This article describes the development and initial validation of a new measure on objective burden in partners of HF patients. The final inventory is presented as a promising self-report instrument to assess the objective demands on partners of HF patients.

Principal component analysis deduced 38 independent care giving tasks out of the initially 50 care giving tasks that were assessed. Component analysis indicated that four meaningful, independent components of care giving tasks could be identified. The components proved to be internally consistent and uni-dimensional and evidence for sufficient reliability was found.

The objective burden inventory provides information on the total amount of care giving tasks that partners perform, it can differentiate into specific kinds of

care giving tasks that are performed and which of these tasks are experienced as most burdensome. In our study population a limited number of personal or physical care tasks are performed, most care giving tasks were related to emotional and practical support. This underlines the importance of including these kind of care giving tasks in an inventory on objective burden.

The inventory is developed to assess the objective burden of partners of HF patients and contains items that are specifically applicable to partners of HF patients such as for example the disease related tasks. However, many of the tasks that are assessed may also be applicable to partners of patients with other chronic diseases. It may be worthwhile to investigate the usefulness of the DOBI in other partner-populations.

As Karmilovich [11] found significant differences in the number of performed care giving tasks between male and female partners, our results show that this may be true for certain kinds of care giving tasks. Although correlations were weak, female partners tended to perform more motivational care tasks and male partners tended to perform more care giving tasks regarding personal care. Female partners tended to report more task related burden which is in line with earlier findings. [8,11,27]

The associations that were found with related constructs provided preliminary evidence for the validity of the components. A worse health status of the HF patient seemed to increase the amount of care giving demands regarding personal care. The same relationship was found between mental health of the patient and increased amounts of emotional support.

Our data also confirmed earlier findings [13] that objective burden and subjective burden seem to be partly different concepts. Performed care giving tasks was associated with task related burden but only to some extent meaning that task related burden can only partly be explained by the kind and number of care giving tasks. The same pattern was found for correlation coefficients between performed care giving tasks and subjective burden as measured by the CRA. In future research it is important to investigate which factors mediate the relationship between objective burden, task related burden and subjective feelings of burden.

Although the DOBI appears to be a promising instrument to assess objective burden, there are points for improvement and further testing is needed. A confirmatory analysis on an independent sample of HF partners is needed to confirm the existence and reliability of the subscales. Furthermore, our study population was predominantly female (75%) and therefore the number of male partners was too small to test for gender independence. However, the composition of the components may be different for male and female partners. Finally, our study population consisted of HF partners that were caring for a HF patient for at least one year. The inventory was completed at home with the patient in a relatively stable condition. It would be of importance to test the inventory in different situations to explore it sensitivity to events and different stages of the disease.

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References

1 Berkman LF. The role of social relations in health promotion. *Psychosom Med* 1995; 57:245-54.
2 Reifman A. Social relationships, recovery from illness, and survival: A literature review. *Ann Behav Med* 1995; 17:124-31.
3 Chin MH & Goldman L. Correlates of early hospital readmission or death in patients with congestive heart failure. *Am J Cardiol* 1997; 79:1640-44.
4 Krumholz HM, Butler J, Miller J, Vaccarino V, Williams CS, Mendes de Leon CF, Seeman TE, Kasl SV, Berkman LF. Prognostic importance of emotional support for elderly patients hospitalized with heart failure. *Circulation* 1988; 97:958-64.
5 Luttik ML, Jaarsma T, Veeger NJGM, van Veldhuisen D. Marital Status, Quality of Life and Clinical Outcome in patients with Heart Failure. *Heart & Lung* 2006; 35:3-8.
6 Molloy GJ, Johnston DW, Witham MD. Family caregiving and congestive heart failure. Review and analysis. *Eur J Heart Fail* 2005; 7:592-603.
7 Evangelista LS, Dracup K, Doering L, Westlake C, Fonarow GC, Hamilton M. Emotional well-being of heart failure patients and their caregivers. *J Cardiac Fail* 2002; 8:300-5.
8 Rohrbaugh MJ, Cranford JA, Shoham V, Nicklas JM, Sonnega JS, Coyne JC. Couples coping with congestive heart failure: role and gender differences in psychological distress. *J Fam Psychol* 2002; 16:3-13.
9 Luttik ML, Jaarsma T, Veeger NJGM, van Veldhuisen DJ. For better and for worse: Quality of life impaired in HF patients as well as in their partners. *Eur J Cardiovasc Nurs* 2005; 4:11-4.
10. Schulz R, Beach SR. Caregiving as a risk factor for mortality: the Caregiver Health Effects Study. *JAMA* 1999; 282:2215-9.
11 Karmilovich SE. Burden and Stress Associated with Spousal Caregiving for Individuals with Heart Failure. *Prog Cardiovas Nurs* 1994; 9:33-8.
12 Scott LD. Caregiving and care receiving among a technologically dependent heart failure population. *Adv Nurs Sci* 2000; 23:82-97.
13 Montgomery RV, Stull DE, Borgatta EF. Measurement and the analysis of burden. *Res Aging* 1985; 7:137-52.
14 Kinsella G, Cooper B, Picton C, Murtagh D. A review of the measurement of caregiver and family burden in palliative care. *J Palliat Care* 1998; 14:37-45.
15 Robinson BC. Validation of a Caregiver Strain Index. *J Gerontol* 1983; 38:344-48.
16 Given CW, Given B, Stommel M, Collins C, King S, Franklin S. The caregiver reaction assessment (CRA) for caregivers to persons with chronic physical and mental impairments. *Res Nurs Health* 1992; 15:271-83.
17 Nijboer C, Triemstra M, Tempelaar R, Sanderman R, van den Bos GA. Measuring both negative and positive reactions to giving care to cancer patients: psychometric qualities of the Caregiver Reaction Assessment (CRA). *Soc Sci Med* 1999; 48:1259-69.
18 Stewart S, MacIntyre K, Hole DJ, Capewell S, Mc Murray JJ. More 'malignant' than cancer? Five-year survival following a first admission for heart failure. *Eur J Heart Fail* 2001; 3:315-22
19 Wal MHL, van der, Jaarsma T, Veldhuisen van DJ. Non-compliance in patients with heart failure; how can we manage it? *Eur J Heart Fail* 2005; 7:5-17.

20 Stetz KM. Caregiving demands during advanced cancer. The spouse's needs. *Canc Nurs* 1987; 10:260-68.
21 Duijnstee MSH, Cuijpers WMJ, Humbert MJ, Dungen van den AWL. Mantelzorg voor mensen met een chronische ziekte. 1994. Zoetermeer, Nationale Commissie Chronisch Zieken.
22 Timmermans JM. Mantelzorg. 2003. Den Haag, Sociaal Cultureel Planbureau.
23 Remme WJ, Swedberg K. Guidelines for the diagnosis and treatment of chronic heart failure. *Eur Heart J* 2001; 22:1527-60.
24 Jaarsma T, van der Wal MH, Hogenhuis J, Lesman I, Luttik ML, Veeger NJGM, Veldhuisen van DJ. Design and methodology of the COACH study: a multicenter randomised Coordinating study evaluating Outcomes of Advising and Counselling in Heart failure. *Eur J Heart Fail* 2004; 6:227-33.
25 Field A. Discovering Statistics. 2005. Sage Publications, London.
26 Kiers A. Simulateous Components Analysis, version 1.02. Groningen, The Netherlands, ProGAMMA 1990.
27 Yee JL, Schulz R. Gender differences in psychiatric morbidity among family caregivers: a review and analysis. *Gerontologist* 2000; 40:147-64.
28 Pinquart M, Sorensen S. Differences between caregivers and noncaregivers in psychological health and physical health: a meta-analysis. *Psychol Aging* 2003; 18:250-67.
29 Zee K, van der Sanderman R, Heyink J. A comparision of two multidimensional measures of health status; the Nottingham Health Profile and the RAND 36-item Health Survey 1.0. *Qual Life Res* 1996; 5:165-74.
30 Radloff L.The CES-D scale: A self-report depression scale for research in the general population. *Applied Psychological Measurement* 1977; 1:385-401.

Subjective Caregiver Burden:
limited influence of disease severity

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Submitted

Abstract

Background

In complying with required life style changes Heart Failure (HF) patients often depend on their partners. However, providing care may cause burden and affect the health of these partners. This study aims to investigate determinants of caregiver burden in order to identify caregivers who are at risk.

Methods

Using a cross-sectional design, caregiver burden and potential determinants were measured in partners of HF patients. Demographic and clinical data of HF patients were assessed and partners completed questionnaires on caregiver burden (the Caregiver Reaction Assessment CRA), performed caregiving tasks, physical and mental health status and quality of the marital relationship.

Results

In total 357 partners (75% female, mean age 67 years) participated. The physical health status of HF patients was only significantly associated with two domains of caregiver burden, 'disruption of daily schedule' ($p<0.01$) and 'loss of physical strength' ($p<0.01$). No associations were found with age, comorbidity and LVEF. All domains of the CRA were mainly associated with the partner's own mental health ($p<0.01$) and with providing personal care to HF patients ($p<0.01$). Gender differences were only found with regard to the domain of 'feeling a lack of family support'.

Conclusion

The assessment of caregiver burden should focus on the mental strength of partners. Furthermore, when assistance in personal care is needed, additional support, either informal or professional, may be indicated.

Introduction

Managing the consequences of Heart Failure (HF) is a complex issue for patients [1] and social support, especially the support of an intimate partner, is essential. The availability of supportive relations has proven to affect patient outcome in terms of quality of life [2] rehospitalization rates [3,4] and mortality. [3-5]

However, the burden of providing care to a chronically ill partner affects the health and well-being of these partners. Research in populations with varying chronical conditions has shown that providing care to a chronically ill family member contributes to physical morbidity and even to mortality in caregivers. [6,7] The results of the few studies that have been conducted within the field of HF, indicate increased levels of psychosocial distress, [6,8,9] decreased levels of well-being [10,11] and impaired Quality of Life (QoL). [12] These adverse effects may eventually undermine the capacity of the couple to cope with the disease.

Because of the beneficial effects on patient outcome, partners of patients with HF warrant the attention of health care providers. Better understanding of caregiver burden and its determinants is essential to identify and support caregivers who are at risk.

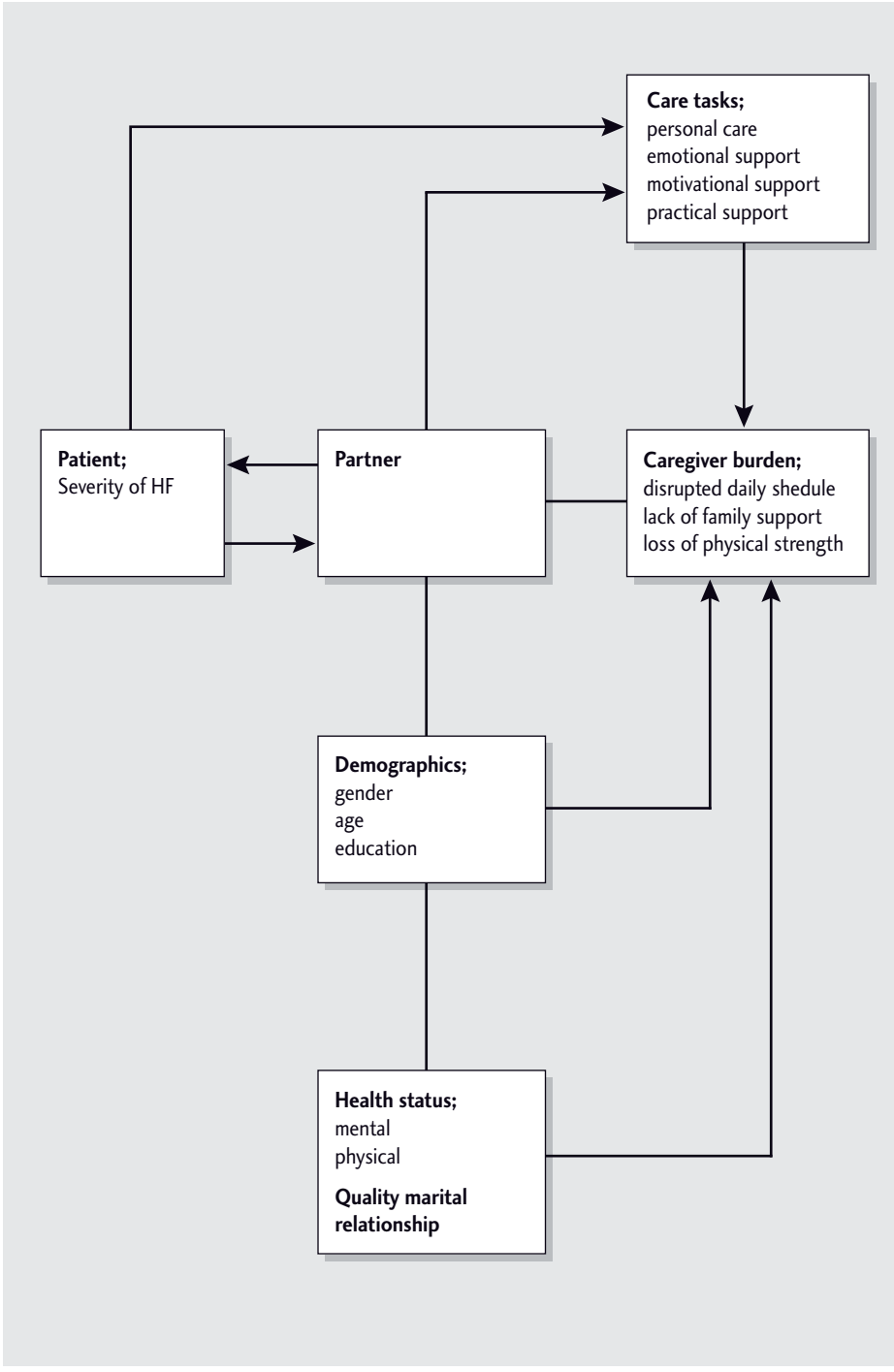
Clinicians in general are primarily aimed at the patient and the patient's environment is often considered from the patient's perspective. From that point of view it seems logical to assume that more severe HF will indicate higher levels of impairment, placing more demands on the caregiver which will cause caregiver burden. However, from research in other chronically ill populations it is known that disease severity is only partly associated to caregiver burden. [13] Within the field of HF conflicting results are reported on the relationship between severity of HF and caregiver burden. [8,9,14-16]

Although it seems evident that the level of patient impairment is directly related to the amount of caregiving tasks, the effect of different types of caregiving tasks on burden experienced by caregivers is less clear. Caregiving tasks and feelings of burden are only moderately associated and the same amount of caregiving tasks may result in different levels of caregiver burden. [17]

In studying determinants of caregiver burden, other variables have to be considered as well. Demographic factors such as gender [8,9,18,19,20] and age [6,16,20] are known to be related to caregiver burden. Furthermore, the partner's own physical and mental health status and the perceived quality of the marital relationship are expected to be associated with feelings of caregiver burden. [13]

The **purpose of this study** is to investigate the relative impact of disease severity, objective caregiving demands and caregiver characteristics on levels of subjective caregiver burden (figure 1).

Figure 1. Research model



Methods

Subjects

The study population consisted of partners of HF patients that participated in the Dutch NHF-COACH trial on the effects of advising and counselling in HF patients. [21] Summarized, the following inclusion and exclusion criteria were used: all patients were admitted for HF (NYHA II-IV); patients were at least 18 years of age, with evidence of structural underlying heart disease; all partners were approached 12 months after the HF patient was discharged from the initial hospitalization. There were no specific in or exclusion criteria except for partners to be able and willing to complete a questionnaire.

Procedure

Clinical data and demographics were collected by chart review and patient interview at baseline, during hospital admission of the HF patients. One year after discharge partners received self-report questionnaires at home, which they were asked to complete independently from the patient. Additional data on the patient's health status at 12 months were collected during visits at the outpatient clinic. Independent interviewers collected the questionnaires by visiting partners at home.

Measurements

Outcome variable

The perceived caregiver burden was assessed by the Caregiver Reaction Assessment scale (CRA). [22] This instrument proved to be a valid instrument for assessing caregiver experiences in partner caregivers of cancer patients [23] as well as in partners of other chronically ill patient populations. [22] The CRA consists of five subscales which reflect different domains of caregiver burden and can be used independently. For the aim of this study we used three subscales. The domain 'disrupted daily schedule' measures the extent to which caregiving interrupts the caregiver's own daily activities. 'Lack of family support' measures the extent to which the caregiver experiences a shortage of family support and feels that taking care of the patient is his of her exclusive responsibility. The domain 'loss of physical strength' assesses the impact of caregiving on the physical health of the caregiver. For each domain, the total score was computed as the average of the subsequent item scores, ranging from 1.0-5.0, with a higher score representing a higher burden.

Independent variables

Severity of disease was assessed by different measures. Left Ventricular Ejection Fraction (LVEF) was assessed at baseline of the NHF-COACH trial. The subscale physical functioning of the RAND 36 questionnaire, a measure of general health [24] was assessed at 12 months after discharge of the initial hospitalization. Scores on the physical functioning subscale range from 0 – 100 with 100 indicating optimal physical condition.

Also the duration of HF and comorbidity were assessed.

The *performed caregiving tasks* were assessed by the Dutch Objective Burden Inventory (DOBI). The DOBI assesses 38 different kind of caregiving tasks partners which can be divided into 4 domains; personal care (13 items), treatment related (practical) assistance (20 items), emotional support (6 items) and motivational support (11 items). For each domain a total score was computed as the average of the subsequent items ranging range from 1.0 to 3.0, with a higher score meaning more caregiving tasks performed. Initial evaluation supported the reliability (alpha varying from .80 to .89) and validity of the subscales. [25]

Demographic variables (age, gender and educational level) were assessed at baseline during baseline interviews with the patient. *Caregiver's health status* was assessed by two subscales of the RAND 36 questionnaire, the subscales on physical and mental functioning. [24]

The perceived quality of the *marital relationship* was assessed using a Ladder ranging from 0 to 10 based on the Cantril ladder. [26] A score of 10 represents the best imaginable quality of the relationship, 0 represents the worst imaginable relationship. A global measure of relationship quality allows respondents to base their judgements on aspects of their relationship that are most important to them. [27]

Statistics

All data were entered into an SPSS database and analysed using descriptive statistics to describe the study population. As for number of comorbidities we included diabetes, rheumatic diseases, stroke and COPD in a categorical variable. Continuous variables that were not normally distributed were categorized in dichotomous or categorical variables. First differences in caregiver burden scores were tested univariately by using ANOVA techniques. The general linear model module of SPSS was used to built three different models, with each subscale of the CRA as the dependent variable. The variables for which burden scores univariately differed significantly were entered into the linear model. An overall significance level of 0.05 was used. Gender was forced into all three regression analyses because of its known effect on caregiver burden.

Results

Respons

In total 403 questionnaires were send out between February 2003 and November 2005, 378 (94%) questionnaires were returned. Thirteen partners (3%) appeared to be not able to complete the questionnaire because of their own deteriorated health status. Ten (3%) partners indicated that it was too much trouble or that it was perceived as a stressful confrontation. In 10 cases (3%), reasons for non-respons remained unclear and in total thirteen questionnaires (3%) were incomplete and could not be used.

Study population

The study population consisted of 357 HF partners. Partners and patients had a mean age of 67 and 68 years respectively. Partners were predominantly female (75%), most couples (96%) were married and thirteen couples were living together (not married). Fifty-four percent of the HF partners had a low (no education-primary school-vocational school) educational level. As shown in Table 1, the mean left ventricular ejection fraction was 32% and the mean score on the subscale Physical Functioning of the RAND 36 was 48.5 (±29). Forty-five percent of the HF patients had one or more comorbidities such as diabetes (22%) and COPD (25%). All patients were non-hospitalized at the time of the partner questionnaire.

The mean scores on the caregiver reaction assessment scale are presented in table 2. Highest caregiver burden score was on the domain 'disrupted daily schedule', lowest score on 'lack of family support'. In total 23% of the HF partners indicated disruption in daily activities because of the caregiving responsibilities. Sixteen percent indicated a lack of family support and 20% indicated a loss of physical strength as a result of the caregiving process.

Partners of HF patients do not perform many tasks in personal care such as bathing and dressing (table 3). The main emphasis is on practical and treatment related tasks such as achieving medication or observing HF symptoms, and on providing emotional support.

Table 1. Partner and patient demographic and clinical characteristics (n357)

Partner characteristics	
Age (yrs ±sd)	67 ±12
Gender (female)	75%
Low educational level	54%
Physical Functioning[1]	70 ±27
Mental Functioning[1]	74 ±19
Quality of the marital relationship[2] (median (33th and 67th percentile))	8.0 (8.0, 9.0)
Patient characteristics	
Age (yrs ±sd)	68 ±11
Gender (female)	25%
Physical Functioning[2]	48 ±29
LVEF (%)	32 ±14
Duration of Heart Failure	
≤ 18 months	60%
> 18 months	40%
Number of co morbidities	
None	53%
One	31%
Two or more	14%

[1] *theoretical range 0-100,* [2] *theoretical range 0-10*

Table 2. Mean Caregiver Burden scores

CRA subscales[1]	Mean (sd)
Disrupted daily schedule	2.3±0.8
Lack of family support	2.2±0.7
Loss of physical strength	2.3±0.8

[1] *theoretical range 1-5*

Table 3. Mean scores performed caregiving tasks

Performed caregiving tasks[1]	Mean (sd)
Personal care	1.2 ±0.3
Motivational support	1.4 ±0.4
Emotional support	1.8 ±0.5
Practical support	1.9 ±0.5

[1] *theoretical range 1-3*

Univariable analysis

As shown in table 4, most prominent differences in caregiver burden scores were found for partner characteristics. Low physical, low mental health and low perception of the marital relationship revealed significantly higher caregiver burden scores. The performance of different kinds of caregiving tasks resulted in significantly different caregiver burden scores for all three CRA domains. In reference to patient characteristics, limited differences were found for severity of disease, in terms of physical functioning and duration of HF. No differences were found for LVEF, comorbidity and age.

Multivariable regression analysis

The variables that added significant value to the multivariable model of 'disrupted daily schedule' were: severity of HF in terms of physical functioning (ß =-0.14, p<0.001 per 25 units on physical functioning), the performance of caregiving tasks (personal care ß =-0.33, p<0.001, emotional support ß =0.17, p<0.05 and practical support ß=0.34, p<0.001) and the partner's mental health (ß=-0.25, p<0.001 per 25 units on mental functioning). Forty percent of the total variance in this domain of caregiver burden was explained by the identified variables.

Burden in terms of 'lack of family support' was significantly associated with gender (ß =-0.22, p<0.01), the partner's mental health (ß =-0.21, p<0.001, per 25 units on mental functioning) and the performance of personal care tasks (ß=-0.20, p<0.01). However, the final model explained only 13% of the total variance in this CRA domain.

Variables that added significant value to the multivariable model of 'loss of physical strength' were mainly the physical and mental health of the partner (ß =-0.27, p<0.001 and ß =-0.37, p<0.001 respectively, per 25 units on physical

and mental functioning). Furthermore, the performance of personal care tasks was significantly associated (ß =-0.15, p=0.05). Forty-five percent of the variance in this subscale was explained by the identified variables.

Table 4. Univariate relationships between CRA domains and potentially associated factors

		Disrupted daily schedule		Lack of family support		Loss of physical strength	
		Mean/β	p-value	Mean/β	p-value	Mean/β	p-value
Severity of disease							
LVEF	≤ 40	2.4	0.19	2.2	0.71	2.3	0.55
	> 40	2.5		2.2		2.3	
Physical functioning[1]		-0.28	<0.001	-0.05	0.14	-0.17	<0.001
Duration of HF	< 18 months	2.3	0.03	2.2	0.24	2.3	0.33
	> 18 months	2.5		2.3		2.3	
Comorbidities	none	2.3	0.11	2.2	0.60	2.3	0.62
	1	2.5		2.2		2.3	
	>2	2.3		2.3		2.3	
Performed caregiving tasks							
Personal care	low intensity[2]	2.0	0.00	2.1	0.00	2.1	0.00
	high intensity	2.7		2.3		2.5	
Emotional support[3]		0.56	0.00	0.01	0.84	0.18	0.03
Motivational support							
	low intensity[2]	2.1	0.00	2.2	0.04	2.2	0.01
	high intensity	2.6		2.3		2.4	
Practical support[3]		0.62	0.00	0.18	0.02	0.12	0.17
Partner characteristics							
Age	≤ 70	2.4	0.44	2.3	0.05	2.3	0.58
	> 70	2.3		2.1		2.3	
Gender	male	2.3	0.85	2.0	0.00	2.2	0.30
	female	2.3		2.3		2.3	
Education	low	2.3	0.91	2.2	0.70	2.4	0.00
	high	2.3		2.2		2.1	
Physical functioning[1]		-0.07	0.05	-0.05	0.24	-0.32	<0.001
Mental functioning[1]		-0.38	<0.001	-0.25	<0.001	-0.47	<0.001
Quality marital relationship							
	0-7	2.5	0.03	2.3	0.01	2.5	0.01
	8	2.3		2.2		2.2	
	9-10	2.2		2.1		2.2	

[1] *β for the univariate regression analysis per 25 units on the RAND 36 (physical functioning and mental functioning)*

[2] *β for the univariate regression analysis*

[3] *above/below the median score: personal care; median=1.0, motivational support; median= 1.3*

Table 5. Multivariable linear regression models

Independent variables	Outcome variables					
	Disrupted daily schedule $R^2=0.40$		Lack of family support $R^2=0.13$		Loss of physical strength $R^2=0.45$	
	ß	p-value	ß	p-value	ß	p-value
Severity of Heart Failure						
LVEF	-	-	-	-	-	-
Physical functioning[1]	-0.14	< 0.001	-	-	-0.07	0.03
Duration of HF (≤18 months)[2]	-0.02	0.82	-	-	-	-
Number of comorbidities	-	-	-	-	-	-
Performed caregiving tasks						
Personal care (low intensity)[2]	-0.33	< 0.001	-0.20	0.009	-0.15	0.05
Emotional support	0.17	0.04		-	0.03	0.70
Motivational support (low intensity)[2]	-0.08	0.30		-	-0.06	0.39
Practical support	0.34	< 0.001	0.06	0.46	-	-
Partner characteristics						
Age	-	-	-	-	-	-
Gender (male)[2]	-0.005	0.95	-0.22	0.008	-0.02	0.81
Educational level (low)[2]	-	-	-		0.12	0.07
Physical functioning[1]	-0.03	0.39	-	-	-0.27	< 0.001
Mental functioning[1]	-0.25	< 0.001	-0.21	<0.001	-0.37	< 0.001
Quality marital relationship[2]						
0-7	0.18	0.06	0.12	0.21	0.16	0.06
8	0.03	0.69	0.08	0.31	0.07	0.34

[1] *increase in CRA per 25 units of the RAND 36 (physical functioning and mental functioning)*

[2] *non presented β is zero*

Discussion

The present study is one of the first to investigate feelings of caregiver burden in partners of HF patients. We tried to elucidate which factors are associated with caregiver burden and to define the impact of patient's disease severity. The main finding of the present analysis is that patient's disease severity is not an important issue related to caregiver burden. More important variables to consider are the partner's own mental health and providing personal care to HF patients.

Although univariately we found significant associations between severity of disease and caregiver burden, in a multivariable model this variable contributed only to a small extend. Consistent with Karmilovich, [8] we found no relationship between LVEF, as a measure of HF severity, and caregiver burden. More surprisingly we also did not find a relationship between comorbidity and the amount of caregiver

burden, although comorbidities were present and are related to more complex care.

The fact that partners have to perform caregiving tasks is also related to feelings of burden, especially when it concerns tasks regarding personal care such as assisting with washing and bathing and moving in and around the house.

Gender differences are known to be present in feelings of distress in spousal caregivers [8,9,18,19] with women reporting more distress than men. We found no gender differences in caregiver burden in terms of disruption of daily activities or loss of physical strength. However, gender differences were present in caregiver burden defined as feeling a lack of family support with women reporting higher scores on this caregiver burden domain. This finding is consistent with earlier studies that indicate women reporting a higher need for social support than men. [18]

Attempts to explain gender differences in spousal distress have focused on the relationship with the quality of the marital relationship. [5,9] Rohrbaugh [9] suggests that gender differences probably can be explained by marital quality. The findings of our study do not confirm this suggestion. The quality of the marital relationship did not contribute significantly to any of the domains of caregiver burden. Although low perceived marital quality versus high perceived marital quality was borderline significant. A possible explanation may be in the way quality of the marital relationship was measured, as a single-item score, and the lack of variance in this score. This may also relate to the way that marital quality was assessed. Patients and partners were instructed to complete the questionnaire independently from each other, but since questionnaires were completed at home without the researcher being present, there is no guarantee that these instructions were followed precisely and consequently.

Our study was one of the first to measure burden related to the caregiving proces. Only one study in HF partners is known [28] measuring the concept of caregiver burden. In this study scores on the CRA subscales seem higher (only percentages are described) compared to our study population, however this may be due to the study population which consisted of partners of patients with end-stage HF patients receiving intensive home treatment. Caregivers in our study population indicated less problems on 'disrupted daily schedule' and 'loss of physical strength' compared to partners of patients with stroke or rheumatoid arthritis. [29] Scores on the subscale 'lack of family support' were comparable. Burden in HF partners was comparable to burden in partners of patients with cancer. [23] These findings are at least remarkable considering the severe debilitating impact of HF along with the grim prognosis.

Some limitations of our study need to be mentioned. The use of a cross sectional design limits the findings to the level of associations between variables. In the future, prospective studies are necessary to unravel the exact nature of the relationship between caregiver burden and partner's health status. Furthermore, as in much caregiver research, our population consisted of merely women. Future research should attempt to include male caregivers in order to really explore their specific experience.

Conclusion

Neither severity of HF, comorbidity nor age are primary factors to assess when judging the family situation on its capability to care for the patient with HF. The focus should be on the mental and physical health status of caregivers. Furthermore, when patients are deteriorating to a level where personal care is needed, it is important to initiate support from others, either informal or professional.

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References

1 Wal van der MHL, Jaarsma T, Moser DK, Veeger NJGM, van Gilst WH, van Veldhuisen DJ. Compliance in heart failure patients: the importance of knowledge and beliefs. *Eur Heart J* 2006; 27:434-40

2 Bennett SJ, Perkins SM, Lane KA, Deer M, Brater DC, Murray MD. Social support and health-related quality of life in chronic heart failure patients. *Qual Life Res* 2001; 10:671-82.

3 Chin MH, Goldman L. Correlates of early hospital readmission or death in patients with congestive heart failure. *Am J Cardiol* 1997; 79:1640-4.

4 Krumholz HM, Butler J, Miller J, Vaccarino V, Williams CS, Mendes de Leon CF, Seeman TE, Kasl SV, Berkman LF. Prognostic importance of emotional support for elderly patients hospitalized with heart failure. *Circulation* 1998; 97:958-64.

5 Coyne JC, Rohrbaugh MJ, Shoham V, Sonnega JS, Nicklas JM, Cranford JA. Prognostic importance of marital quality for survival of congestive heart failure. *Am J Cardiol* 2001; 88:526-9.

6 Pinquart M, Sorensen S. Differences between caregivers and noncaregivers in psychological health and physical health: a meta-analysis. *Psychol Aging* 2003; 8:250-67.

7 Vitaliano PP, Zhang J, Scanlan JM. Is caregiving hazardous to one's physical health? A meta-analysis. *Psychol Bull* 2003; 129:946-72.

8 Karmilovich SE. Burden and Stress Associated with Spousal Caregiving for Individuals with Heart Failure. *Prog Cardiovasc Nurs* 1994; 9:33-38.

9 Rohrbaugh MJ, Cranford JA, Shoham V, Nicklas JM, Sonnega JS, Coyne JC. Couples coping with congestive heart failure: role and gender differences in psychological distress. *J Fam Psychol* 2002; 16:3-13.

10 Dracup K, Evangelista LS, Doering L, Tullman D, Moser DK, Hamilton M. Emotional well-being in spouses of patients with advanced heart failure. *Heart Lung* 2004; 33:354-61.

11 Evangelista LS, Dracup K, Doering L, Westlake C, Fonarow GC, Hamilton M. Emotional well-being of heart failure patients and their caregivers. *J Card Fail* 2002; 8:300-5.

12 Luttik ML, Jaarsma T, Veeger NJ, van Veldhuisen DJ. For better and for worse: Quality of life impaired in HF patients as well as in their partners. *Eur J Cardiovasc Nurs* 2005; 4:11-4.

13 Nijboer C, Tempelaar R, Sanderman R, Triemstra M, Spruijt RJ, van den Bos GA. Cancer and caregiving: the impact on the caregiver's health. *Psychooncology* 1998; 7:3-13.

14 Martensson J, Dracup K, Canary C, Fridlund B. Living with heart failure: depression and quality of life in patients and spouses. *J Heart Lung Transplant* 2003; 22:460-7.

15 Molloy GJ, Johnston DW, Witham MD. Family caregiving and congestive heart failure. Review and analysis. *Eur J Heart Fail* 2005; 7:592-603.

16 Pihl E, Jacobsson A, Fridlund B, Stromberg A, Martensson J. Depression and health-related quality of life in elderly patients suffering from heart failure and their spouses: a comparative study. *Eur J Heart Fail* 2005; 7:583-9.

17 Montgomery RV, Stull DE, Borgatta EF. Measurement and the analysis of burden. *Res Aging* 1985; 7:137-52.

18 Lutzky SM, Knight BG. Explaining gender differences in caregiver distress: the roles of emotional attentiveness and coping styles. *Psychol Aging* 1994; 9:513-9.

19 Yee JL, Schulz R. Gender differences in psychiatric morbidity among family caregivers: a review and analysis. *Gerontologist* 2000; 40:147-64.
20 Barusch AS, Spaid WM. Gender differences in caregiving: why do wives report greater burden? *Gerontologist* 1989; 29:667-676
21 Jaarsma T, van der Wal MH, Hogenhuis J, Lesman I, Luttik ML, Veeger NJGM, Veldhuisen van DJ. Design and methodology of the COACH study: a multicenter randomised Coordinating study evaluating Outcomes of Advising and Counselling in Heart failure. *Eur J Heart Fail* 2004; 6:227-33.
22 Given CW, Given B, Stommel M, Collins C, King S, Franklin S. The caregiver reaction assessment (CRA) for caregivers to persons with chronic physical and mental impairments. *Res Nurs Health* 1992; 15:271-83.
23 Nijboer C, Triemstra M, Tempelaar R, Sanderman R, van den Bos GA. Measuring both negative and positive reactions to giving care to cancer patients: psychometric qualities of the Caregiver Reaction Assessment (CRA). *Soc Sci Med* 1999;48:1259-69.
24 Zee K vd, Sanderman R., Heyink J. A comparision of two multidimensional measures of health status; the Nottingham Health Profile and the RAND 36-item Health Survey 1.0. *Qual Life Res* 1996; 5:165-174.
25 Luttik M.L., Jaarsma T., Tijssen J., van Veldhuisen D.J. The objective burden in partners of Heart Failure patients; development and validation of the Dutch Objective Burden Inventory (DOBI) (abstract) *Eur J Cardiovasc Nurs* 2006; suppl 38.
26 Cantril H. The pattern of human concerns. New Brunswick: Rutgers University; 1965.
27 Kuijer RG, Buunk BP, De Jong GM, Ybema JF, Sanderman R. Effects of a brief intervention program for patients with cancer and their partners on feelings of inequity, relationship quality and psychological distress. *Psychooncology* 2004; 13:321-34.
28 Scott LD. Caregiving and care receiving among a technologically dependent heart failure population. *ANS Adv Nurs Sci* 2000; 23:82-97.
29 van Exel NJ, Brouwer WB, van den BB, Koopmanschap MA, van den Bos GA. What really matters: an inquiry into the relative importance of dimensions of informal caregiver burden. *Clin Rehabil* 2004; 18:683-93.

General Discussion

Discussion

Bringing up partners of HF patients as a subject of interest in the field of cardiology is quite new and initially it brings about feelings of unease and maybe for some, even irritation. Clinicians are primarily focused at patients and their disease parameters. They are focused on the control of vital signs, chest pain, optimizing medication, ejection fractions, ECG's and laboratory work. They aim at optimizing and stabilizing the physical condition in order to improve survival, to prevent rehospitalization and optimize quality of life. In this context there is little concern about psychosocial issues like if patients are anxious, depressed or compliant, let alone that there is any concern about the role and well-being of their partners.

It is now more and more recognized that HF patients need extensive advising and counselling in learning to cope with their disease and the prescribed treatment. Multidisciplinary disease management programs have been developed implemented and have proven to be effective. [1-3] With nurses playing an important role in these programs, a holistic approach can be expected, with concern for the patient's physical and mental condition. Nurses talk with patients about how they manage, they support patients in the management of medication, the monitoring of symptoms and their activity level. In addition they talk with patients about the difficulties they meet in daily life and about their fears for the future. However, nurses also seem to feel reluctant to mention the role and well-being of partners. Do we have to bother about them too? Nurses recognize problematic patient–partner communication and unsupportive behaviour of partners but still these problems are hardly discussed nor 'treated'. Partly this may be related to cultural history, in the clinical setting nurses are also primarily focused at patients, their disease and its treatment. But for some part it seems that nurses also feel uncomfortable to bring up this subject, let alone to interfere; 'where will we end up if we are going to talk about partners and how patients and partners communicate together?' or 'how should we do this, we are not educated to assess or counsel marital relationships'

Here the lack of evidence based methods seems to play a role. Psychosocial factors are still difficult to assess and interventions are thought to be time consuming and not adequately proven to be effective. [4]

In this thesis we addressed the question of why we **should** be concerned about the role and well-being of partners when counselling HF patients. Furthermore, if we are concerned and determined to support patients and partners as a couple, we have to investigate the impact of HF on the lives of partners.

Part I

What is the importance of a having a partner in terms of health outcome in patients with Heart Failure?

Main findings

The literature overview in chapter 3 reports on 17 studies investigating the relationship between social support and different outcome parameters in patients with Heart Failure (HF). Compared to other illness groups little research has been done into this area yet.

Four studies revealed hard evidence [5-8] for decreased readmission rates and lower mortality for patients with supportive relationships. The number of studies regarding the relationship between social support and quality of life (QoL) and social support and depression was very limited and did not reach firm conclusions.

A secondary analysis on data of a Dutch population of patients with HF showed a trend towards less hospitalizations for patients living with a partner. Differences in QoL scores were found with lower QoL scores for HF patients who were living alone. However, these differences were merely related to factors like gender, age and socioeconomic status

Conclusions

It can be concluded that like in other populations of chronically ill, social support is important for patients with HF as well. Reduced mortality and hospitalization rates were found in patients who receive (emotional) support from partners, family or friends. In our study we could not confirm these results, probably because the study did not have enough power. We did find that patients who live alone are at risk for lower perceived QoL scores, merely because of the fact that most of these patients are elderly females with a low socioeconomic status. In the near future, the NHF-COACH follow-up database will provide us with comprehensive data in a large population of patients and partners and will allow us to re-address this question with a more powerful dataset.

Part II

How does giving care to patients with HF affect the lives of partners?

Main findings

Chapter 6 reports low QoL scores for HF patients in the period before and during hospitalization for HF. Even lower scores were found for partners of these patients, not only during hospitalization but also related to future expectations. These findings strongly suggest a negative influence of HF on the lives of partners. Chapter 5 underlines these findings with solid examples of how the lives of partners are affected. Many changes had to be faced especially at the onset of

the disease. Disease specific aspects were mentioned such as anxiety, the need to restructure daily life and mutual communication on the process of adapting to new patterns in life. In chapter 7 the objective burden of partners of HF patients is quantified in the variety and number of caregiving tasks that partners perform. As no instruments were available at the time, a new inventory was developed. The Dutch Objective Burden Inventory (DOBI) consists of 38 items divided into four clusters; (1) tasks regarding personal care, (2) emotional support, (3) motivational support and (4) practical or treatment related support. Initial psychometric testing of the inventory showed promising results. Final scores show that the main emphasis in the care for patients with HF is on practical or treatment related support and on emotional support.

In chapter 8 subjective feelings of caregiver burden were measured with the Caregiver Reaction Assessment scale. Our study is one of the first to measure caregiver burden as a concept within a population of partners of patients with HF. Twenty-three percent of the partners indicated disruption of their own activities, 20% indicated a loss of physical strength as a result of being a caregiver. These scores were comparable to partners of patients with cancer. The partner's own mental health status and the performance of tasks regarding personal care were the most strongly related variables.

Conclusions

As very little is known on the effect of HF on the caregiving partners, this study adds to the building of knowledge and evidence in this area. The diagnosis of HF seems to affect the lives of partners seriously, as reflected in low QoL scores and in the stories that partners reported during interviews. Partners have to perform caregiving tasks mainly with regard to practical and treatment related aspects such as the diet and the medication supply. Furthermore, they provide the patient with emotional support, which proved to be extremely important in earlier research, [6] and they try to stimulate the patient in complying with their lifestyle prescriptions.

Feelings of subjective caregiver burden were measured and for 20-23% of the caregiving partners scores did reflect burden. The scores probably reflect the process of adaptation that some of the partners had to go through. Some partners succeeded in adapting quite well, while others were still struggling and reported burden. A weak mental health of the caregiving partner and the need for assistance in personal care in HF patients were the most provoking factors for reporting feelings of burden.

Implications for future research

It is clear that when advances in medical treatment for patients with HF become limited, care becomes more and more important. This care primarily needs to be focused on optimizing the treatment regimen and on compliance with medical prescriptions.

Future research should focus on the content of interventions, on determining how health behaviour in terms of adhering to medical prescriptions can be positively affected. In order to be really effective in obtaining behavioural changes, psychosocial factors need to be considered. [9]

We now know that the availability of a partner benefits HF patients in managing their disease, in preventing rehospitalization and improving their prognosis. Therefore the issue of partner support needs further investigation.

1 Which interventions are effective in optimizing partner support?

The mechanism of how support from a partner relates to health outcome is still not clear but one of the hypotheses is that partners actually influence the health behaviour of patients either by their own health behaviour or by their concrete support. It is of importance to further investigate how partners can influence patient behaviour in terms of adhering to the prescribed HF treatment regimen.

Our study on performed caregiving tasks indicated that partners mainly perform practical and treatment related tasks. To be able to provide optimal support, partners need to be actively involved in the care for HF patients. There should be explicit focus on partners in terms of education specifically on HF treatment issues, like a sodium-restricted diet or symptom monitoring. A recent randomized trial on the effects of a caregiver intervention in caregivers of stroke patients by training them to provide care effectively, resulted in positive outcome in terms of health care costs, caregiver burden and patient psychosocial outcomes. [10] The content of such an intervention should contain disease specific aspects. Whereas the main emphasis within the population of stroke partners was on assistance in personal care, within the population of HF partners the focus should be more on how to influence healthy behaviour like taking exercise, to stop smoking and following a healthy diet.

A (patient-)partner intervention should provide knowledge on the treatment of HF, symptom monitoring and compliance to lifestyle prescriptions. Attention should be paid to the way patients and partners cope individually and to the way patients and partners support each other. Although nurses hesitate to get involved in this area, they are explicitly fit to discuss these issues. Nurses traditionally are characterized by their holistic approach and by being easy accessible for patients. They should take advantage of these qualities and apply them in discussing the importance of patient-partner communication and mutual support in an easy atmosphere. By discussing these issues in the beginning problematic behaviour can be detected in an early stage and even prevented in the future. In the context of the multidisciplinary approach in most HF clinics, psychologists and social workers can be consulted or referred to when complex psychosocial problems or psychopathology are present.

Nurses need tools to assess the strength and capabilities of partners and the effectiveness of patient-partner communication. Furthermore, elementary nurse-led interventions that optimize the supportive role of partners need to be developed and evaluated on their effectiveness in terms of patient and partner health outcome.

2 What is the impact of marital quality on effective partner support?

From literature in MI patients and their partners it is learned that partners are not always supportive.[11] Overprotectiveness from partners is often suggested as a potentially serious form of problematic social support. As it was expressed in our interviews with partners, anxiety may cause this protective behaviour and may hamper effective coping with the disease.

The quality of the marital relationship is known to play a pivotal role in the caregiving process and proved to be an important factor influencing prognosis in HF patient.[12,13] Conflicts that may arise from inadequate supportive behaviour, cause stress and increase the risk of cardiovascular events. This underlines the aforementioned that interventions to support patients and their partners should include behavioural aspects regarding how couples can support each other effectively in the integration of the disease in their lives.

In this respect it will also be important to make a distinction between male-patient and female-patient couples. Research has indicated that women profit less from their marital relationship in terms of health effects than men do. Women are more likely to control another person's health; thus when marriage promotes better health habits, these effects will be relatively larger for men than for women.[14] As a result men and women probably need different interventions in the empowerment of their caregiving capacities.

3 Further exploration of disease specific aspects in caregiver burden in HF partners is needed

The concept of caregiver burden has hardly been addressed in research on cardiovascular care and a disease specific instrument to measure caregiver burden in partners of HF patients was not available. Since anxiety and marital communication on the restructuring of daily activities, as they appeared in the study presented in this thesis, were not included as aspects of caregiver burden in the CRA, we strongly suggest further research in this area.

One of the advantages of the CRA is that it also measures positive dimensions of caregiver reactions. In the caregiver literature studies increasingly report on the subjective, beneficial effects of caregiving. In this thesis this aspect may be underexposed, although we certainly recognized positive feelings derived from giving care to the HF patient from the interviews and also in the CRA scores on the subscale 'care-derived self-esteem'.

4 Dynamics of caregiver burden and the impact of events like hospitalization should be explored

Christakis[15] investigated the association between hospitalization of chronically ill patients and mortality in partners. Hospitalization of patients increased the risk of death in their partners, for patients with HF a 12% increase of risk (HR 1.12) was found. Our findings of very low levels of QoL scores in HF partners during hospitalization may be an indication of these results. Since hospitalization still is very common in patients with HF further research on the effects of hospital

admission on couples is recommended. Furthermore, the dynamics of patient and partner health and caregiver burden over time needs to be investigated in prospective studies and the influence of events like acute physical deterioration and hospitalization needs to be determined.

5 What is the role of gender in perceived caregiver burden?
As women are underexposed in medical, cardiovascular research, so are men in the field of research on caregiving. For a long time cardiovascular disease was more prevalent in men than in women and for that reason men were overrepresented in most of the pharmaceutical cardiovascular trials. Now it is recognized that the prevalence of cardiovascular disease is growing in women and along with that the conviction that evidence for treatment strategies should be re-considered for female HF patients. In the same way research on the caregiving situation in patients with HF is overrepresented by female caregivers. Future research should actively attempt to include male caregivers in order to really explore their specific experiences and needs for support.

6 Prospective studies on caregiver burden and health outcome are necessary
Finally, in this thesis caregiver burden and factors of influence were studied in a crosssectional design. Referring to the conceptual model mentioned in the introduction, we investigated associations between the different concepts. In chapter 8 we reported on the association between caregiver burden and partner characteristics. Further research is needed to unravel causality of associations between for example caregiver burden and health outcome. Does a weak mental or physical health of caregivers cause caregiver burden, or is it caregiver burden that leads to a decrease in mental and physical health? And probably more importantly, should interventions be aimed at decreasing caregiver burden or on promoting mental health? Does this mean that different interventions are needed? The NHF-COACH data base contains comprehensive and valuable data for further research in this area.

Implications for health care

While it is obvious that the HF patient will remain the main focus of health care professionals, it is also inevitable to recognize the reciprocal effects of the disease on partners in order to really understand the progress of the disease. Health care professionals, especially those involved in counselling patients in the management of their disease, have to broaden their scope towards caregivers or partners. It is important that partners are being recognized as essential in the care for patients. They have to be actively involved which should be more than just being present incidentally, listening while the patient receives education and counselling. Partners probably should be obliged to be present during the first series of visits at the heart failure clinic or at the heart failure nurse. During these

visits there should be explicit focus on the role of partners and their individual capacity to meet the caregiving demands that are placed on them. The partner's own mental status proved to be important for caregiver capacity and moreover the amount of caregiving tasks regarding personal care may trigger the onset of caregiver burden.

A recent study of Christakis [15] suggests that the riskiest time for partners, in terms of their own health, is just after hospitalization of the patient they are caring for. This indicated that interventions to support partners should match with such events.

A second issue that we like to address here is the fact that within this thesis we focused on patients with HF who were living with a partner, which appeared to be the case in about 57% of the total population. As a consequence, this means that 43% of the patients with HF is living alone and is probably even more at risk of developing complications and rehospitalization. As we described in chapter 3, these patients appeared to be mainly elderly women. With the current perspectives on future epidemiology in HF, predicting a growing amount of elderly women with HF, this should be a point of concern in health care practice.

References

1 McAlister FA, Fiona ME, Lawson MB, Koon KT, Armstrong PW. A systematic review of randomized trials of disease management programs in Heart Failure. *Am J Med* 2001; 110:378-84.

2 Gustafsson F, Arnold JM. Heart Failure clinics and outpatient management: review of the evidence and call for quality assurance. *Eur Heart J* 2004; 25:1596-67.

3 Whellan DJ, Hasselblad V, Peterson E, O'Connor CM, Schulman KA. Metaanalysis and review of heart failure disease management randomized controlled clinical trials. *Am Heart J*, 2005; 4:722-29.

4 Moser DK. Psychosocial factors and their association with clinical outcomes in patients with heart failure: why clinicians do not seem to care. *Eur J Card Nurs*, 2002; 1:183-88.

5 Chin MH, Goldman L. Correlates of early hospital readmission or death in patients with congestive heart failure. *Am J Cardiol* 1997; 79:1640-44.

6 Krumholz HM, Butler J, Miller J, Vaccarino V, Williams CS, Mendes de Leon CF, Seeman TE, Kasl SV, Berkman LF. Prognostic importance of emotional support for elderly patients hospitalized with heart failure. *Circulation* 1998; 97:958-64.

7 Murberg TA, Bru E. Social relationships and mortality in patients with congestive heart failure. *J Psychosom Res*; 51:521-27

8 Coyne JC, Rohrbaugh MJ, Shoham V, Sonnega JS, Nicklas JM, Cranford JA. Prognostic importance of marital quality for survival of congestive heart failure. *Am J Cardiol* 2001; 88:526-29.

9 Hemmingway H, Marmot M. Psychosocial factors in the aetiology and prognosis of coronary heart disease; systematic review of prospective cohort studies. *BMJ*, 1999; 318:1460-67

10 Kalra A, Evans A, Melbourn A, Patel A, Knapp M, Donaldson N. Training carers of stroke patients: randomised controlled trial. *BMJ*; 328:1099.

11 Moser DK. Social support and cardiac recovery. *J Cardiovasc Nurs* 1994; 9:27-36

12 Waltz M. Marital context and post infarction quality of life: is it social support or something more? *Soc Sci Med* 1986; 22:791-805

13 Coyne JC, Rohrbaugh MJ, Shoham V, Sonnega JS, Nicklas JM, Cranford JA. Prognostic importance of marital quality for survival of congestive heart failure. *Am J Cardiol* 2001; 88:526-29.

14 Umberson D. Gender, marital status and the social control of health behavior. *Soc Sci Med* 1992; 4:907-17.

15 Christakis NA, Allison PD. Mortality after the hospitalization of a spouse. *N Engl J Med* 2006; 54:719-30.

Summary

Technological developments in the past decades have resulted in many new treatment options for patients with cardiovascular diseases. As a consequence there is a growing amount of patients that have to learn to live with irreversible, chronic conditions such as heart failure (HF). Although options for medical treatment for patients with HF have also increased in the past decades, the prognosis for these patients remains poor. At the same time, HF patients place a significant economic burden on the health care system because of their frequent need for hospital admission. At this moment there is a growing conviction that the efforts to improve patient outcome should focus on the advising and counselling of patients in how to adapt to their disease in daily life. Compliance and optimal lifestyle changes will lead to better outcome in terms of mortality, readmission rate, and quality of life.

Although professional care is needed, the support from the patient's social environment such as partners and family is equally important. There is growing evidence that social support is essential for adjustment to illness and that a lack of support may result in deterioration, complications and other health risks. At the same time, trends in our current health care system such as the ageing of the population and early discharge policies, place a growing demand on informal carers. The work of informal carers is increasingly recognized as an important pillar in the health care system and therefore paying attention to the role and well-being of partners and family is important. At this moment very little research is done on the situation of partners and family of HF patients.

The thesis addresses two main research questions;

1 What is the impact of having a partner for patients with heart failure in terms of health outcome?
2 In what way does giving care to patients with heart failure affect the lives of partners?

Chapter 2 describes the methodology of the NHF-COACH study which provided the context for the substudy on partners. The Coordinating study evaluating Outcomes of Advising and Counselling in Heart failure (COACH) is a multicenter randomized trial evaluating the effectiveness of two different levels of advising and counselling of HF patients compared to care as usual (consult of a cardiologist every 6 months). It is hypothesized that the advising and counselling of HF patients will have a positive effect on mortality, readmission rates and quality of life in a 18 months follow-up period. In addition, the underlying mechanisms such as compliance, knowledge and self-care behaviour that lead to the potential success of the intervention are studied. Another factor that may influence potential results is the amount of support that patients receive from their social environment. A substudy on partners and partner support of the participating NHF-COACH patients is conducted. Data were collected on the supportive role of partners and on the way this affected the partner's well being.

Part I

Part I of this thesis aims at the first research question; the impact of social support or, more specifically, on having a partner on the progress of HF.

Chapter 3 describes current research on the influence of social support on outcomes in HF. A computerized literature search in Medline, CINAHL and PsychLit was performed on each of the different outcomes in relation to social support, covering the period 1993 to 2003. In total 17 studies were found that investigated the relationship between social support and different outcome measures in HF. In four studies a clear relationship was found between social support and rehospitalization and mortality. Lack of social support and social isolation were found to be independent risk factors for rehospitalization and mortality. The relationship between Quality of Life (QoL) and depression was less clear and no firm conclusions can be drawn yet.

In conclusion, limited research has been done on the impact of social support on outcomes in patients with HF but the available studies suggest a relationship between the amount of social support and health outcomes (re-admission rate and mortality) in patients with HF.

In *Chapter 4* we investigated the impact of having a partner on Quality of Life (QoL), the number of hospital readmissions, and 9-months survival in patients with HF. Data of an earlier intervention study in patients with HF in the Netherlands, were re-analyzed. The study population consisted of hospitalized HF patients and QoL was measured by the Cantril Ladder of Life (0-10).

Of the 179 patients, 96 (54%) were married or were living with a partner. Significant differences were found in the background variables of both groups; patients that were living alone appeared to be merely elderly female with lower socio-economic status. Married patients had 12% less events in the 9-months follow-up period compared to patients living alone. Furthermore, married patients reported a higher QoL compared to patients who were living alone. However, in a multivariate model QoL was primarily associated with socioeconomic status, age and gender.

This study indicates that HF patients who are living with a partner have better health outcome, although this seems to be merely associated with the differences in age, gender and socioeconomic status between both groups. HF patients who are living alone are mostly elderly women with a low socioeconomic status, who are at risk for recurrent events and a worse QoL.

Part II

The second part of the thesis addresses the question whether and how the lives of partners are affected by the disease of the HF patient.

Chapter 5 describes a series of interviews specifically focused on the experiences of partners of HF patients. The interviews took place at the homes of

partners without the patient being present. Results show that the lives of partners are seriously affected. Partners describe changes in their daily life and in their relationship with the patient. Also different ways of coping with the consequences of the disease and different kinds of perceived support are described. Partners support patients in their daily activities; they often change their own daily schedule and have to adapt their joint activities. Regaining a new balance together is one of the challenges that couples face when confronted with heart failure. Anxiety is an important theme, sometimes interferring with adequate coping strategies, especially in the acute phase. Changes in relationship were related to difficulties in communication and sexuality.

Although most partners seem to cope relatively well with the impact of HF on their life they are vulnerable especially at the onset of the disease. It seems important to involve partners actively in the process of rehabilitation and to recognize their importance and their potential problems.

In *Chapter 6* the QoL of partners of HF patients is explored and compared to the QoL of the patients. Again the database of the earlier Dutch intervention study in HF patients was used. The study population consisted of 38 couples of hospitalized HF patients and their partners. The Cantril's Ladder of Life was used to rate QoL during hospitalization, with regard to the month before hospitalization and as projected three years in the future. The QoL scores for HF patients were low, ranging from 4.9 to 6.8. However, the QoL of partner was also low (5.9 to 6.4) and at some point, during hospitalization even lower than the patient's QoL (5.9 vs. 6.8), even after correcting for age and gender. The results of this study provide us with a strong indication of the burdensome influence of HF on the lives of partners.

Whereas in chapter 5 and 6 serious consequences of the disease for the lives of partners are described, *Chapter 7 and 8* focus on the supportive role and the consequences of this role on partners. In literature on informal care and caregiver burden a difference is made between objective caregiver burden and subjective caregiver burden. Objective burden refers to concrete tasks that need to be performed by caregivers. The performance of these tasks may lead to the subjective experience of burden.

Chapter 7 reports on the development and testing of an inventory to assess the concrete caregiving tasks that are performed and the task related burden that is experienced by partners of HF patients. To develop the inventory, items were generated from existing scales, literature and expert opinion. The original 50-item self-report inventory was administered to 321 partners of HF patients. Principal component analysis led to exclusion of 12 original items and to a meaningful four-component solution with a total explained variance of 43%. The components reflected four different kinds of care giving tasks: personal care, emotional support, motivational support and practical support. Final scores on the components show that in caring for patients with HF the main emphasis is on emotional support and practical tasks. Support in personal care was least often performed.

C*hapter 8* aimed to investigate the amount subjective caregiver burden in partners of HF patients and factors that are associated with caregiver burden in order to identify caregivers who are at risk. Caregiver burden was measured using the Caregiver Reaction Assessment scale (CRA) in 357 NHF-COACH patients. At the same time potentially associated factors (severity of HF, kind and amount of performed caregiving tasks, quality of marital relationship and partner characteristics such as physical and mental health) were measured. In total 20-23% indicated burden especially on disruption of their daily schedule and loss of physical strength as a result of the caregiving demands. These burden scores are comparable with the results of studies performed among partners of patients with cancer but they are lower compared to the burden scores among partners of stroke patients.

The physical health status of HF patients was only partly associated with subjective caregiver burden and no associations were found for age and number of comorbidities. Gender differences were only found with regard to the domain of 'feeling a lack of family support' with female partners having higher scores in this domain. All domains of the CRA were mainly associated with the partner's own mental health and with providing personal care to HF patients. The caregiver's mental strength is an important factor to consider when assessing potential feelings of burden. Furthermore, when assistance in personal care is needed, additional support, either informal or professional, may be indicated.

In *Chapter 9* the most important results are described and discussed. Implications for future research and clinical practise are suggested. In general it can be stated that this thesis adds to a new field of interest within the care for patients with HF. Psychosocial factors are extremely important to consider when optimizing care for patients with HF, because these factors determine to a high degree the way that patients will cope with their disease and the prescribed treatment. The extent to which patients are supported by their partners or family is one of the factors that need to be considered. More research is needed on the different kinds of support, on the dynamics of social support in the progress of the disease and on interventions to optimize partner support.

Achtergrond

De technologische ontwikkelingen van de afgelopen decennia hebben geleid tot sterk verbeterde medische technieken en behandelingsmogelijkheden waardoor vooral binnen de cardiologie steeds meer mensen behandeld kunnen worden. Steeds meer patiënten overleven, vaak echter wel met chronische fysieke consequenties zoals bijvoorbeeld hartfalen (HF). Hoewel de behandelingsmogelijkheden van HF in de laatste decennia sterk zijn toegenomen, blijft de prognose voor deze patiënten matig tot slecht. Tegelijkertijd legt deze categorie patiënten een groot beslag op de capaciteit van de gezondheidszorg vooral door het hoge percentage ziekenhuisopnames. Er is dan ook een groeiende overtuiging dat de inzet van de gezondheidszorg zich moet richten op het begeleiden van patiënten bij het leren omgaan met de ziekte en de gevolgen daarvan voor het dagelijks leven. Optimale leefstijl en therapietrouw zullen leiden tot betere uitkomsten in termen van sterfte en het aantal heropnames maar vooral ook tot behoud of verbetering van kwaliteit van leven.

Naast professionele zorg zijn hulp en ondersteuning vanuit de directe sociale omgeving, van partners en familie onontbeerlijk. Uit onderzoek in gezonde populaties maar ook uit onderzoek onder chronisch zieken, is gebleken dat sociale steun van groot belang is en dat gebrek aan steun kan leiden tot achteruitgang, complicaties en andere gezondheidsrisico's. Tegelijkertijd wordt als gevolg van een aantal maatschappelijke trends (vergrijzing en kortere opname duur) een steeds groter beroep gedaan op mantelzorgers. Mantelzorg is dan ook een uiterst belangrijke pijler in het hedendaagse gezondheidszorgsysteem. Aandacht voor de ondersteunende rol en het welzijn van partners en familie is dan ook van groot belang. Tot op heden is er echter nog nauwelijks onderzoek gedaan naar de specifieke situatie van partners van patiënten met HF.

Hieruit voortvloeiend kent dit proefschrift twee centrale vraagstellingen:
- Wat is de invloed van het hebben van een partner op gezondheidsuitkomsten van patiënten met HF?
- Op welke manier beïnvloedt het leven met en het zorgen voor een patiënt met hartfalen het leven van deze zorgende partners?

Hoofdstuk 2 beschrijft de methodologie van het COACH-onderzoek (Coordinating study evaluating Outcomes of Advising and Counselling in Heart failure) waarbinnen het huidige partner onderzoek heeft plaats gevonden. Het COACH-onderzoek bestaat uit een gerandomiseerde multi center trial waarbij de effectiviteit van twee verschillende zorgprogramma's voor patiënten met HF wordt onderzocht. Twee verschillende interventies (basis zorg en intensieve zorg) worden vergeleken met de standaardzorg zoals die op dit moment gebruikelijk is in Nederland (halfjaarlijkse controle bij de cardioloog). Verondersteld wordt dat beide interventies positieve

invloed hebben op de mortaliteit, het aantal heropnames en de kwaliteit van leven in de 18 maanden durende follow-up periode.

Tevens wordt binnen deze studie onderzocht welke onderliggende mechanismen leiden tot effectiviteit van de interventie. Gedacht wordt dan aan therapietrouw, kennis van hartfalen en zelfzorggedrag. De mate waarin patiënten steun ondervinden van hun partner zou een belangrijke beïnvloedende factor kunnen zijn voor het al of niet succesvol zijn van de interventie strategieën. Gekoppeld aan de geincludeerde patiënten met HF, zijn ook de partners van deze patiënten benaderd. Gegevens zijn verzameld door middel van vragenlijsten die enerzijds gericht waren op de zorgtaken die partners verrichten ten behoeve van de patiënt, anderzijds is gevraagd naar de ervaren belasting en het welzijn van deze partners.

Deel I

Het eerste deel van dit proefschrift richt zich op de vraag in hoeverre sociale steun of meer specifiek het hebben van een partner, van belang is voor het ziekteverloop van patiënten met HF.

Hoofdstuk 3 geeft een overzicht van de literatuur betreffende onderzoek naar de relatie tussen sociale steun en gezondheidsuitkomsten bij patiënten met HF.

Een literatuur search in Medline, CINAHL en PsychLit naar de relatie tussen sociale steun en de verschillende uitkomstmaten voor patiënten met HF laat zien dat op dit gebied slechts in zeer beperkte mate onderzoek is gedaan, in totaal werden 17 studies gevonden.

Vier daarvan waren prospectieve studies welke een duidelijke relatie laten zien tussen het ontvangen van sociale steun, het aantal heropnames en overleving in de tijd. Gebrek aan sociale steun of sociale isolatie bleek een onafhankelijke risicofactor voor heropname en overlijden. De relatie sociale steun en kwaliteit van leven is minder goed onderzocht waardoor een conclusie hier minder duidelijk te trekken is. Voor de relatie tussen sociale steun en het voorkomen van depressie geldt dat op dit gebied weinig onderzoeksresultaten werden gevonden. De onderzoeken die zijn gedaan wijzen op een positieve relatie tussen het ontvangen van sociale steun en herstel van depressie.

Concluderend kan worden gesteld dat de onderzochte studies wijzen op een sterke relatie tussen sociale steun en gezondheidsuitkomsten bij patiënten met HF in termen van het aantal heropnames en overleving, vergelijkbaar met de resultaten zoals gevonden in andere chronisch zieke patiëntenpopulaties.
In *hoofdstuk 4* wordt verslag gedaan van een secundaire analyse op onderzoeksgegevens van een zorgstudie onder patiënten met HF in Maastricht.

In dit hoofdstuk gaat het om de vraagstelling of patiënten die leven met een partner een betere kwaliteit van leven ervaren, minder vaak worden heropgenomen in een follow-up periode van 9 maanden en wellicht langer (of meer) overleven in diezelfde periode, vergeleken met patiënten zonder partner.

Van de 179 patiënten leefde iets meer dan de helft (96) met een partner. De univariate vergelijking van beide groepen patiënten laat zeer duidelijke demografische verschillen zien. De groep alleenstaanden patiënten blijkt vooral te bestaan uit oudere vrouwen met een lage sociaal economische status. Hoewel het verschil statistisch niet significant is, blijkt dat in de groep patiënten met een partner, minder patiënten zijn overleden en/of werden heropgenomen (12%) in de 9 maanden follow-up periode. Tevens beoordeelde deze groep patiënten zijn of haar kwaliteit van leven significant hoger dan de groep alleenstaanden. In een multivariate analyse blijkt dit verschil echter vooral samen te hangen met de verschillen in demografische achtergrond zoals geslacht, leeftijd en sociaal economische status.

Concluderend laat de studie zien dat de groep patiënten die leeft met een partner het op verschillende uitkomstmaten beter doet in vergelijking met alleenstaande patiënten, hetgeen voor een deel samenhangt met de verschillen in demografische kenmerken.

Deel II

In deel II van dit proefschrift gaat het vooral om de vraag of en hoe het leven met een patiënt met HF het leven van de partner beïnvloedt.

Hoofdstuk 5 beschrijft een serie interviews met partners van patiënten met HF. De interviews vonden plaats in de thuissituatie zonder de aanwezigheid van de patiënt. De interviews waren expliciet gericht op de ervaringen en eventuele behoeften van partners.

Uitkomsten van deze interviews laten zien dat het leven van partners eveneens ingrijpend verandert nadat de diagnose hartfalen is vastgesteld. Partners beschrijven veranderingen in hun dagelijks leven, veranderingen in hun relatie met de patiënt, verschillende manieren om met deze veranderingen om te gaan (copinggedrag) en over de steun die zij ontvangen vanuit hun omgeving. Partners ondersteunen de patiënt in het omgaan met de ziekte, vaak moeten zij hun eigen activiteiten patroon veranderen en aanpassen. Het samen hervinden van een nieuwe balans is een belangrijke uitdaging voor de patiënt en diens partner. Verder lijkt angst een belangrijke rol te spelen vooral in de acute, beginfase van de ziekte. Deze angst kan goede coping in de weg staan. Ook veranderingen in de relationele sfeer vooral die op het gebied van onderlinge communicatie en ook seksualiteit worden genoemd.

Hoewel een deel van de partners goed lijkt kunnen omgaan met de impact van HF op zijn of haar leven vormen zij wel een kwetsbare groep vooral in de beginfase nadat de diagnose is vastgesteld. Het is dus belangrijk om partners actief te betrekken bij de voorlichting en het proces van revalidatie en de rol van deze partners bij het leren omgaan met de ziekte te erkennen en potentiële problemen bij deze partners tijdig te signaleren.

In *hoofdstuk 6* is de kwaliteit van leven van partners van patiënten met HF met behulp van kwantitatieve gegevens onderzocht en vergeleken met de kwaliteit van leven van de patiënt.

Opnieuw is gebruik gemaakt van data uit de Maastrichtse zorgstudie. Kwaliteit van leven werd gemeten met behulp van de Cantril Ladder of Life (score tussen 0 en 10). Patiënten en partners gaven een cijfer aan hun kwaliteit van leven op het moment van de ziekenhuisopname, maar ook aan hun kwaliteit van leven in de maand voor de ziekenhuisopname en voor over 3 jaar in de toekomst.

In totaal zijn de kwaliteit van leven scores van 38 patiënten en hun partners gemeten en vergeleken. De gegevens laten zien dat patiënten laag scoren, tussen de 4.9 en 6.8. Partners scoren echter eveneens laag (5.9 tot 6.4) en wanneer het gaat om kwaliteit van leven tijdens de heropname zelfs lager dan de patiënt (5.9 vs. 6.8), ook na correctie voor leeftijd en geslacht.

De resultaten van deze studie vormen een indicatie voor de negatieve of belastende invloed van hartfalen op het leven van de partners.

Voorgaande studies (hoofdstukken 5 en 6) hebben aangetoond dat de diagnose hartfalen het leven van partners ingrijpend beïnvloedt. In *hoofdstuk 7 en 8* is de aandacht gericht op wat partners doen in de zorg voor patiënten met HF en de belasting die zij hierbij ervaren. In de literatuur over belasting van mantelzorgers wordt veelal onderscheid gemaakt tussen objectieve en subjectieve belasting. Bij objectieve belasting gaat het om de zichtbare en concrete taken die moeten worden verricht. Het moeten uitvoeren van deze taken kan vervolgens een gevoel van belasting geven, dit wordt de subjectieve belasting of ervaren belasting genoemd.

Hoofdstuk 7 doet verslag van de ontwikkeling (en het testen) van een instrument ten behoeve van de inventarisatie van objectieve zorgtaken van partners van patiënten met HF en de ervaren belasting bij deze zorgtaken.

Met behulp van bestaande instrumenten, literatuur en experts op het gebied van zorg voor patiënten met HF, werden in totaal 50 zorgtaken geformuleerd. Deze 50 zorgtaken zijn verwerkt tot een vragenlijst met behulp waarvan werd nagegaan of de zorgtaak werd verricht en zo ja in hoeverre dit als belastend werd ervaren. De vragenlijst is afgenomen bij 321 partners van NHS-COACH patiënten. Met behulp van factoranalyse is de lijst van 50 zorgtaken gereduceerd tot 38 zorgtaken. Deze 38 zorgtaken kunnen worden ingedeeld in 4 herkenbare clusters; zorgtaken op het gebied van persoonlijke verzorging, emotionele ondersteuning, motiverende steun en praktische of behandelingsgerelateerde taken. De scores van de 321 partners laten zien dat het accent in de zorg voor patiënten met HF ligt op emotionele ondersteuning en praktische of behandelingsgerelateerde zorgtaken. Zorgtaken gericht op persoonlijke verzorging worden weinig verricht.

In *hoofdstuk 8* is onderzocht in welke mate partners van patiënten met HF zich belast voelen en welke factoren samenhangen met deze ervaren belasting. Met behulp van de Caregiver Reaction Assessment scale (CRA) is de ervaren belasting gemeten bij 357 partners van NHS-COACH patiënten. Tegelijkertijd zijn potentieel beïnvloedende factoren gemeten waarbij onderscheid is gemaakt in de ernst van het hartfalen, het soort en aantal zorgtaken door partners verricht, de kwaliteit

van de huwelijksrelatie en een aantal persoonlijke kenmerken van partners. In totaal geeft ongeveer 20% van de partners aan zich belast te voelen vooral wanneer het gaat om verstoring van het eigen activiteiten patroon en de fysieke belasting samenhangend met het zorgen voor de patiënt. De mate van ervaren belasting blijkt vergelijkbaar met die van partners van patiënten met kanker en lager dan die van partners van CVA-patiënten.

De mate van ervaren belasting hangt slechts in beperkte mate samen met de ernst van het hartfalen en er werd geen associatie gevonden tussen de ervaren belasting, leeftijd en het aantal co-morbiditeiten. Geslachtsverschillen zijn er alleen wanneer het gaat om de ervaren steun. Vrouwen ervaren minder steun vanuit hun omgeving bij het zorgen voor de patiënt in vergelijking met mannelijke partners. Het is vooral de eigen mentale en fysieke gezondheid van partners die blijkt samen te hangen met de mate van ervaren belasting. Daarnaast hangt het moeten ondersteunen bij de persoonlijke verzorging van de patiënt eveneens samen met het ervaren van belasting. Het inschatten van de capaciteit en de belasting van de partner dient zich vooral te richten op de mentale conditie van de partner en de behoefte aan ondersteuning in de persoonlijke verzorging bij de patiënt.

In *hoofdstuk 9* worden de belangrijkste resultaten samengevat en bediscussieerd. Implicaties voor toekomstig onderzoek en de klinische praktijk worden beschreven. In zijn algemeenheid kan worden vastgesteld dat dit proefschrift bijdraagt aan een nieuw aandachtsgebied in de zorg voor patiënten met HF. Met het ontwikkelen van optimale zorg voor deze patiëntencategorie dient rekening gehouden te worden met psychosociale factoren omdat deze in hoge mate bepalen hoe patiënten uiteindelijk omgaan met hun aandoening en de bijbehorende behandeling. De mate waarin patiënten steun ontvangen vanuit hun directe omgeving is een belangrijke factor in deze. Meer onderzoek naar de verschillende vormen van steun, naar de dynamiek van sociale steun in het verloop van de ziekte en naar interventies ten behoeve van het optimaliseren van deze steun, is noodzakelijk.

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Curriculum Vitae

Maria Louise Luttik werd geboren op 16 januari 1964 te Zwolle. Na het behalen van haar VWO diploma verhuisde zij naar Groningen, waar zij in 1982 startte met de Hogere Beroepsopleiding voor Verpleegkundigen, welke met goed gevolg werd afgerond in 1986. Hierna trad zij in dienst bij het toenmalig Academisch Ziekenhuis Groningen, nu Universitair Medisch Centrum Groningen. Van 1986 tot 1987 was zij werkzaam als verpleegkundige op de afdeling Neurologie, vanaf 1987 tot 1996 binnen de Beatrix Kinderkliniek. In die periode studeerde zij tussen 1989 en 1993 parttime Gezondheidswetenschappen, afstudeerrichting Verplegingswetenschap aan de Rijksuniversiteit Groningen (in MUG verband). In 1996 maakte zij de overstap naar de functie van wetenschappelijk onderzoeker binnen het Coördinatiecentrum Chronisch Zieken Noord-Nederland (CCZ-NN). Daar was zij betrokken bij evaluatie onderzoek van verschillende projecten zoals o.a. de evaluatie van de cursus omgaan met een chronische aandoening voor patiënten (Multiple Sclerose, COPD en Reuma) en hun partners.
In het jaar 2002 werd zij als een van de onderzoekers aangesteld binnen het COACH onderzoek, gefinancierd door de Nederlandse Hartstichting en geïnitieerd en uitgevoerd vanuit de afdeling Cardiologie van het Thoraxcentrum binnen het UMCG.
Het laatst genoemde project bij het CCZ-NN vormde de directe aanleiding om ook binnen het COACH project aandacht te besteden aan de rol en invloed van partners als belangrijke pijler in de zorg voor patiënten met hartfalen.

1 Luttik ML, Oeseburg B, de Ruiter JH. Intraveneuze thuisbehandeling van MS-patienten met metylprednisolon. Een zorgmodel. *Medisch Contact* 1997; 52: 1427-29.

2 Luttik ML, Oeseburg B, Schure LM, Overberg CMS, Hovius-Dragt R. De cursus 'leven met een chronische ziekte' voor mensen met MS, reuma en COPD en hun partners. Een evaluatie studie. *Verpleegkunde* 2002; 17:77-86.

3 Luttik ML. Ontwikkeling en implementatie van een 'copingtraining'; de cursus 'leven met een chronische ziekte' voor mensen met Multiple Sclerose, reuma en COPD en hun partners. Eindrapportage, ZorgOnderzoek Nederland, 2000

4 Luttik ML, Uyttewaal L, Winter J, de Ruiter JH. Endocarditis thuis behandelen; het kan, maar in beperkte mate. *Medisch Contact* 2000; 55:587-89

5 Oeseburg B, Luttik ML, Schure LM, Overberg CMS, Hovius-Dragt R. Implementatie Cursus Leven met Multiple Sclerose, Reuma en COPD voor patient en centrale verzorger in de eerste lijn. *Tijdschrift voor Sociale Gezondheidszorg* 2001; 79:391-93.

6 Luttik ML, Jaarsma T, van der Wal MHL, Hogenhuis J, Lesman-Leegte I, van Veldhuisen D. Groot landelijk onderzoek naar de effectiviteit voorlichting en begeleiding bij patiënten met hartfalen; Het COACH-onderzoek van start! *Cordiaal* 2003; 4:17-21.

7 Hellema F, Kinds J, Boelens M, Bos I, Luttik ML, Stallinga G, Tijssen G, Visser D, van Vliet G. Dossier Klinisch -2. ICF instrumenten voor continuïteit van zorg. *Tijdschrift voor Verpleegkunde* 2002; 10:55-59.

8 Jaarsma, T., van der Wal, M.H., Hogenhuis, J., Lesman, I., Luttik, M.L., Veeger, N.J. et al. Design and methodology of the COACH study: a multicenter randomised Coordinating study evaluating Outcomes of Advising and Counselling in Heart Failure. *Eur J Heart Fail,* 2004; 6:227-33.

9 Luttik ML, Jaarsma T, Moser DK, Sanderman R, van Veldhuisen DJ. The importance and impact of social support on outcomes in patients with heart failure: An overview of the literature. *Journal of Cardiovascular Nursing* 2005; 20: 162-69.

10 Luttik ML, Jaarsma T, Veeger NJ, van Veldhuisen DJ. For better and for worse: Quality of life impaired in HF patients as well as in their partners. *Eur J Cardiovasc Nurs* 2005; 4:11-4.

11 Luttik M.L., Jaarsma T., Veeger NJ, van Veldhuisen D.J. Marital Status, Quality of Life and Clinical Outcome in patients with Heart Failure. *Heart Lung* 2006; 35:3-8.

12 Luttik ML. Behandelingsgerelateerde zorgtaken van partners van patiënten met hartfalen. *Cordiaal* 2006; 4:60-2

13 Luttik ML, Jaarsma T. The objective burden in partners of heart failure patients; a new inventory. *Eur J Cardiovasc Nurs* 2006; suppl 1:538.

Dutch Objective Burden Inventory (English and Dutch version)

Instruction

With this questionnaire we try gain insight into the care tasks performed by partners of patients with heart failure.
For every care task, we would like you to indicate if, in the previous 3 months, you performed this task (please circle the answer that fits your personal situation)
If your answer is 'never', you can go to the next question.
If your answer is 'sometimes/regularly' or 'often/always' please indicate in the next column how burdensome it was for you to carry out this care tasks

Example

	Never	Sometimes or regularly	Often or always	If yes, how burdensome was this for you? Not at all burdensome	Somewhat burdensome	Extremely burdensome
In the previous 3 months, did you support your partner in:						
1 achieving medication						
2 washing and dressing						

Personal care						
In the past three months, did you support your partner:						
1 in eating and drinking						
2 in washing and bathing						
3 in dressing and un-dressing						
4 in going to the toilet						
5 by assisting with appearance (brushing teeth, nail care, combining hair)						
6 in walking in and around the house						
7 in coming in and out of bed or chair						
8 in walking stairs						
9 by elping to find a comfortable position in bed						

Which of the following statements fits your personal situation?							
10 I have to be available for 24 hours to take care of my partner							
11 my partner also needs my help frequently at night							

Practical and treatment related							
Are you the one that;							
12 performs the light household activities (dusting/doing the dishes)							
13 performs the heavy household activities (vacuuming/washing the floors)							
14 does the shopping							
15 does the finances							
16 is filling in forms of reimbursement							
17 arranges care when necessary							
18 arranges physical aids when necessary							

In the previous three months, did you support your partner:							
19 in achieving new prescriptions for medication							
20 in achieving medication							
21 in contacting a professional in case of questions or problems							
22 by attending conversations with physicians and other health care professionals							

Motivational							
In the previous three months, did you support your partner:							
23 in following the fluid prescriptions							
24 in following the diet prescriptions (e.g. seeking low-salt products, cooking low-salt)							
25 in regular weighing							
26 in following the prescriptions on physical activity and exercise							
27 by motivating to stick to the diet prescriptions							
28 by motivating to quit or reduce smoking							
29 by motivating to activities and exercise							
30 by motivating to take medications (in time)							
31 by motivating to stick to the fluid prescriptions							
32 by motivating to start working again							

Emotional support							
In the previous three months, did you support your partner:							
33 by providing comfort							
34 by talking to reduce anxiety							
35 by talking to reduce depressive feelings							
36 by talking about worries and problems							
37 by showing understanding							
38 by keeping company							

Instructie

Met behulp van onderstaande lijst van zorgtaken proberen wij inzicht te krijgen in de taken die u als partner van een patiënt met hartfalen, vervult.

Wilt u voor iedere taak aangeven of u die in de afgelopen 3 maanden heeft uitgevoerd (maak dan het rondje zwart onder het voor u best passende antwoord) Wanneer u 'nooit' invult kunt u doorgaan naar de volgende vraag.

Wanneer u 'soms/regelmatig'of 'vaak/ altijd' heeft ingevuld, wilt u dan vervolgens in de rechterkolom aangeven hoe belastend u het uitvoeren van deze taak heeft gevonden.

Voorbeeld

	Nooit	Soms/regelmatig	Vaak/altijd	Indien ja, hoe belastend vond u dit? Helemaal niet belastend	Enigszins belastend	Heel erg belastend
Heeft u uw partner, in de afgelopen 3 maanden geholpen bij:						
1 het ophalen van de medicijnen						
2 het wassen en aankleden						

Persoonlijke verzorging						
Heeft u uw partner in de afgelopen 3 maanden geholpen:						
1 bij het eten en drinken						
2 bij het wassen en aankleden						
3 bij het aan- en uitkleden						
4 bij het naar het toilet gaan (op de po gaan)						
5 bij de uiterlijke verzorging (haren kammen, nagels verzorgen, tanden poetsen)						
6 bij het lopen in en om het huis						
7 bij het in en uit de stoel of bed komen						
8 bij het trap lopen						
9 bij het aannemen van een gemakkelijke houding in bed						
Welk van de volgende uitspraken zijn op u van toepassing?						
10 ik moet 24 uur per dag beschikbaar zijn voor de zorg voor mijn partner						
11 mijn partner heeft ook 's nachts regelmatig mijn hulp nodig						

Praktische en behandelingsgerelateerde ondersteuning							
Bent u degene die;							
12 het licht huishoudelijk werk doet (stoffen, afwassen)							
13 het zware huishoudelijke werk doet (stofzuigen, dweilen)							
14 de boodschappen doet							
15 de algemene financiële en administratieve zaken regelt							
16 formulieren ten behoeve van uitkeringen en vergoedingen invult							
17 zorgt dat er hulp komt, wanneer dat nodig is							
18 eventueel hulpmiddelen en aanpassingen aanvraagt							

Heeft u uw partner in de afgelopen 3 maanden geholpen:							
19 bij het aanvragen van nieuwe recepten voor medicijnen							
20 bij het kopen en/of ophalen van de medicijnen							
21 bij het inschakelen van een hulpverleners bij vragen en/of problemen							
22 het bijwonen van gesprekken met artsen en andere hulpverleners							

Motiverende ondersteuning							
Heeft u uw partner in de afgelopen 3 maanden ondersteund in de vorm van:							
23 bij het volgen van de voorschriften over de in te nemen hoeveelheid vocht							
24 bij het volgen van het voorgeschreven dieet (bijv zoutarme produkten zoeken, zoutarm koken)							
25 bij het regelmatig wegen							
26 bij het uitvoeren van de voorgeschreven lichamelijke activiteit en/of bewegingsoefeningen							
27 het motiveren tot het volhouden van het voorgeschreven dieet							
28 het motiveren tot het stoppen met roken of het verminderen van het roken							
29 het motiveren tot activiteiten en beweging							
30 het motiveren tot het (op tijd) innemen van de medicijnen							
31 het motiveren tot het volhouden van de voorgeschreven adviezen met betrekking tot de hoeveelheid in te nemen vocht							
32 motiveren tot het weer beginnen met werken							

Emotionele ondersteuning							
Heeft u uw partner in de afgelopen 3 maanden ondersteund in de vorm van:							
33 troost bieden							
34 praten om angst te verminderen							
35 praten om somberheid te verminderen							
36 praten over zorgen en problemen							
37 begrip tonen							
38 gezelschap houden							